



This work is protected by copyright and other intellectual property rights and duplication or sale of all or part is not permitted, except that material may be duplicated by you for research, private study, criticism/review or educational purposes. Electronic or print copies are for your own personal, non-commercial use and shall not be passed to any other individual. No quotation may be published without proper acknowledgement. For any other use, or to quote extensively from the work, permission must be obtained from the copyright holder/s.

A Sociological Study of Social Resources and the Patient Experience of Multiple Chronic Illnesses

Tom Porter

A thesis submitted for the degree of Doctor of Philosophy

April 2015

Keele University

Abstract

The number of people living with multiple chronic illnesses (multimorbidity) is increasing and this trend is set to continue. In recent years, there has been a significant increase in epidemiological and clinically informed research into this patient population. However, the extant literature offers relatively little insight into how lay individuals make sense of multimorbidity.

Social resources, or the physical and emotional sustenance provided by others, are recognised increasingly as a means towards affecting health outcomes. Social resources are apparent as a nascent theme at the levels of health and social care policy, service organisation, and increasingly, at the level of primary care delivery. However, the apparent enthusiasm for social resources is not universal, and critics have questioned both the socio-political motives behind this trend as well as its underlying social theory.

This study employs in-depth qualitative interviews and applies an interpretive approach to analysis. 15 participants living with (at least) osteoarthritis and cardiovascular disease took part in up to two interviews. In addition, a small number of participants' spouses (four) were recruited into the study.

Findings illustrate the ways in which lay individuals make sense of multimorbidity. This thesis draws attention to certain biomedical assumptions made by clinically informed literature. These assumptions are discussed with regard to the concept of illness prioritisation and the relevance of multimorbidity (in conceptual terms) to lay experience.

Findings also illustrate the complexity of social resource exchange during illness. A novel conceptual model is developed to elucidate participants' accounts of supportive practices. Further, findings highlight the role of morality in shaping the experience of support. These observations are synthesised under the theoretical banner of gift-exchange theory, and implications are identified for the application of social resources in policy and service delivery.

Table of Contents

Chapter One: Introduction.....	2
1.1 Introduction	2
1.2 Research questions	4
1.3 The structure of this thesis	5
Chapter Two: Literature review.....	8
2.1 Introduction	8
2.2 The challenge of multimorbidity.....	9
2.2.1 Prevalence, costs and outcomes.....	9
2.2.2 Meeting the challenge of multimorbidity.....	12
2.3 Qualitative studies of multimorbidity.....	13
2.3.1 Multimorbidity and self-management research.....	14
2.3.2 Multimorbidity and illness prioritisation	16
2.4 Social resources and health	20
2.4.1 Social resources in health policy and practice	21
2.4.2 Epidemiological foundations and psychological ‘mechanisms’	24
2.4.3 Social support, social networks and social capital.....	26
2.4.4 Social resources and chronic illness.....	30
2.5 Conclusion and initial research questions	34
Chapter Three: Methodology and study design	37
3.1 Introduction	37
3.2 Philosophical foundations.....	37
3.3 Background to this study	42
3.4 Main study design.....	43
3.5 Pilot study and Research User Group	45
3.6 Sampling and recruitment	47
3.7 In-depth interviews.....	51
3.8 Interviews and social network diaries	52
3.9 Process of analysis	58
3.9.1 Coding practices.....	58
3.9.2 Computer aided qualitative analysis software	60

3.10 Objectivity, reliability and validity in qualitative research.....	61
3.11 Reflexivity.....	63
3.12 Ethical issues	67
3.13 Data management and security.....	68
3.14 Conclusion.....	69
 Chapter Four: The lay meaning of multimorbidity	70
4.1 Introduction	70
4.2 What it means to live with multimorbidity.....	70
4.2.1 Multiple chronic illnesses but not 'ill'	70
4.2.2 Illness without diagnosis or explanation	74
4.3 Lay logics of meaning	78
4.3.1 Normality and control.....	78
4.3.2 Biography and normality.....	84
4.3.3 Ageing and normality.....	88
4.3.4 Lay biomedical knowledge.....	89
4.3.5 Health care professionals.....	92
4.4 Discussion.....	93
 Chapter Five: Social resources: three participant cases	97
5.1 Introduction	97
5.2 Case studies	98
5.2.1 Isla	98
5.2.2 Mary	107
5.2.3 Theo	113
5.4 Discussion.....	119
 Chapter Six: Theoretical review	126
6.1 Introduction	126
6.2 Social capital's conceptual lineage.....	126
6.2.1 The network perspective	127
6.2.2 Individualist social exchange.....	130
6.2.3 Social capital	132

6.3 Gift exchange: an alternative approach.....	136
6.3.1 Mauss' gift.....	136
6.4 Moral economy	139
6.5 Value	143
6.5.2 Symbolic-value	144
6.5.3 Semiotic-value.....	146
6.6 Implications for this thesis	148
 Chapter Seven: The value forms of social resources	149
7.1 Introduction	149
7.2 Use-value	151
7.3 Semiotic-value.....	156
7.4 Symbolic-value	164
7.5 Exchange-value	169
7.6 Social resource exchange: an interpretive economy of meaning.....	172
7.7 Discussion.....	178
 Chapter Eight: Morality, ethical work and social resources	180
8.1 Introduction	180
8.2 The virtue of independence, receiving as erring	181
8.3 Ethical work.....	187
8.4 Co-dependence	197
8.5 Discussion.....	199
 Chapter Nine: Discussion	206
9.1 Introduction	206
9.2 Reflecting upon findings and research questions.....	206
9.2.2 How do people living with multimorbidity make sense of illness and understand their experience of illness as meaningful?	207
9.2.3 How do people living with multimorbidity experience social resources, and the receipt of support and assistance as meaningful?	214
9.3 What does this study add?.....	217
9.4 Policy implications	218
9.5 Future research.....	221

9.6 Conclusion.....	223
References	224

Appendices

Appendix 1:	Baseline participant details
Appendix 2:	Social contact participants list
Appendix 3:	Participant recruitment by mailing batch
Appendix 4:	Invitation letter (patient participant)
Appendix 5:	Invitation letter (social contact participant)
Appendix 6:	Study information leaflet (patient participant)
Appendix 7:	Study information leaflet (social contact participant)
Appendix 8:	Consent form (patient participant)
Appendix 9:	Consent form (social contact participant)
Appendix 10:	Confirmation of interview letter
Appendix 11:	Interview topic guide (patient participant)
Appendix 12:	Interview topic guide (social contact participant)
Appendix 13:	Social network diary cover letter
Appendix 14:	Social network diary
Appendix 15:	Monthly update sheet (patient participant)
Appendix 16:	National Research Ethics Service (NRES) letter 1 (request for further information)
Appendix 17:	NRES letter 2 (confirmation of ethical approval)
Appendix 18:	NRES letter 3 (confirmation of ethical amendment)
Appendix 19:	Example of anonymised interview transcript
Appendix 20:	Publications and presentations arising from this study

List of figures

Figure 1: Study Design Flow Diagram	Page: 44
Figure 2: Interpretive Economy of Meaning	Page: 173

List of tables

Table 1: Baseline participants and recruitment to interviews	Page: 50
--	----------

Acknowledgements

I would like to thank each and every participant who gave up their time and energy and who invited me into their homes; I hope I have been able to tell your stories in an authentic and sincere way.

I am very grateful to Arthritis Research UK for their funding and support during this project. Similarly, to the staff and students of Keele University's Primary Care Research Centre: thank you for your support and guidance. In particular, I would like to express my gratitude to my supervisors, Tom Sanders and Pauline Ong, for their insightful comments and tireless encouragement. Thanks also to those members of the ARUK Primary Care Research Centre's Research User Group, your time and comments were very much appreciated at the inception of this study.

Finally, on a personal note, I would like to thank Mum, Dad, Steph and everyone else who has helped me along the way.

Chapter One: Introduction

1.1 Introduction

This study emerged in response to two prevailing topics of interest: multimorbidity, and the role of social resources in the experience of illness.

In the past decade, multimorbidity has received increasing attention within academic and clinical research and is recognised increasingly within various spheres of health and social care policy. The impetuses behind this focus are familiar: an ageing population, improvements in medical intervention, more effective public health initiatives, and technological advances all contribute towards a situation whereby more people are living with multiple concurrent chronic conditions (Fortin, 2005). To date, multimorbidity has been shown to impact negatively upon a wide range of outcomes including quality of life (QOL), mortality, healthcare utilisation, disability, and adverse complications from treatment effects (Fortin, 2007).¹

The study of people living with more than one disease or chronic condition is not new, and the related term 'co-morbidity' is well-established in medicine and its affiliated sub-disciplines. Co-morbidity was defined originally by Feinstein (1970) as 'any distinct additional clinical entity that has existed or may occur during the clinical course of a patient who has the index disease under study' (Feinstein 1970: 455). Valderas, Mercer, and Fortin (2011), however, describe the emergence of multimorbidity as a 'modern alternative to "comorbidity"', and have argued that that multimorbidity represents a 'more "democratic" approach, [where] no particular condition is privileged over any other' (Valderas, Mercer and Fortin, 2011). In this regard, multimorbidity is seen by many as a

¹ These issues will be addressed in greater detail throughout the literature review chapter of this thesis.

more progressive and realistic (in terms of planning health systems) way of conceptualising illness.

In recent years, a number of studies have begun to explore how multimorbidity is experienced and understood from a lay perspective (in contrast to the clinical perspective identified above). A growing body of literature suggests that multimorbidity presents challenges that are particular and distinct from those experienced during single-condition illness. Studies have claimed to demonstrate that the practices of everyday 'illness work' and self-management are shaped by a particular dynamic stemming from a multiplicity of conditions which are experienced as concurrent. It has been argued that for people living with multimorbidity there is often a necessity to 'prioritise' the self-management of certain conditions at the expense of others (Morris et al., 2011; Kerr et al., 2007). This thesis makes a direct contribution towards this issue, and questions the validity of illness prioritisation as a concept. Specifically, this thesis identifies certain biomedical assumptions which have been accepted tacitly within qualitative studies, and it is argued that these assumptions result in the concept of illness prioritisation being applied inappropriately in self-management literature.

A distinct yet related theme in this thesis concerns the role of social resources and social networks – friends, family, and work colleagues – in shaping the experience of illness . This thesis adopts the definition of social resources contributed by Corbin and Strauss as the 'physical and emotional sustenance' provided by others during illness (Corbin and Strauss, 1988; 109). There is growing consensus across various levels of healthcare policy and organisation that formal services are limited to the extent that they are able to affect positive health outcomes (Cabinet Office [CO], 2011; Coulter, 2009; Institute for Public Policy Research [IPPR], 2009). For a decade or more, calls have been made for health and social care policy and practice to recognise the role played by social resources, and to utilise informal social networks as the basis for intervention and the amelioration of illness (Foot, 2012).

A good deal of sociological research – both theoretical and applied – has considered the role of social networks in shaping the experience of illness. A significant amount of research has been directed towards care giving during older age and illness, and further research has explored how the form and structure of social networks affect the availability and provision of support. Here the most widely invoked sociological contribution continues to be that of social capital. Despite this apparent enthusiasm, however, the socio-political motives for involving social resources in health and social care have been critiqued (Prapthakar, 2013), as has the conceptual apparatus of social capital (Fine, 2010). This thesis draws upon in-depth accounts of people living with multimorbidity, and in doing so highlights several weaknesses inherent to social capital and social network perspectives. As redress, this thesis draws upon diverse sources of social theory to enable an insightful and novel analysis of social resource exchange during illness.

1.2 Research questions

This thesis addresses questions directed at two aspects of illness experience. Firstly, relating to multimorbidity, this thesis asks how people living with multimorbidity experience their illness as meaningful. In answering this question, emphasis will be placed upon how illness is experienced, not just in terms of its symptoms and the individual's engagement with healthcare systems, but rather as situated within individuals' particular social, cultural, and biographical contexts.

Having addressed this question, the larger portion of this thesis concerns social resources and the meaning of supportive practices whilst living with multimorbidity. Here again, an exploratory approach is adopted, and this thesis considers the ways that supportive exchanges are experienced as meaningful in social, cultural, and biographical contexts. Further, these issues will be discussed critically with a view towards the socio-political context of supportive practices. In doing so, this thesis is set apart from a body of literature which has detailed the experience of social support in instrumental terms.

Specific research questions will be outlined in Chapter Two of this thesis.

1.3 The structure of this thesis

The structure of this thesis is as follows:

Chapter Two takes the form of a thematic literature review. This review includes literature from across the social sciences, and also incorporates epidemiological and policy literature. The aim of this chapter is to provide an outline of the salient themes and extant research in the fields of multimorbidity and social resources. This chapter will also detail the specific research questions which this thesis will answer.

Chapter Three outlines the study design and methods adopted within this study. This chapter will also discuss the philosophical underpinnings of this thesis, and will provide an account of epistemological and ontological considerations.

Chapter Four delivers the first findings of this study. This chapter is titled 'The lay meaning of multimorbidity' and reports on the ways participants understood multimorbidity to be meaningful. Emergent themes are discussed in the context of illness self-management which is identified as a salient theme through the literature review of this thesis.

Chapter Five – entitled 'Social resources: three participant cases' – reports on the role of social resources during the experience of multimorbidity. This chapter details three participant's cases and highlights the complexity of supportive practices. In this regard, this chapter poses several conceptual problems which are ill-served by social theory common to the health sciences. Specifically, it will be argued that existing perspectives – particularly that of social capital – fail adequately to conceive of the meaning or value of social resources, and do not sufficiently consider the role of morality in shaping supportive practices.

Chapter Six represents a break in terms of study findings and does not introduce any primary data. Rather, this chapter – entitled 'Theoretical review' – addresses the issues of

value and morality which are identified as problematic in the preceding chapter (Chapter Five). By tracing the conceptual lineage of contemporary perspectives, this chapter makes an argument against theories based upon individualist social exchange. This chapter then introduces parallel theoretical perspectives derived from gift exchange literature. A conceptual framework for value forms based upon the work of Baudrillard (1981) is outlined. Further, the issue of morality is considered with important aspects outlined for consideration in a subsequent results chapter (Chapter Eight).

Chapter Seven is titled 'The value forms of social resources'. This chapter incorporates the conceptual framework outlined in Chapter Six, and argues for social resources being understood according to distinct logics of value: use-value, semiotic-value, symbolic-value, and exchange-value. These logics of value are introduced individually, before being drawn together into a model termed the *interpretive economy of meaning*. This model allows us to consider how the preceding value forms coalesce and intersect during the exchange of support.

Chapter Eight returns to the issue of morality. This chapter is premised upon the argument that reciprocity is an insufficient concept to account for morality in social exchange. This chapter outlines a number of moral principles as they appeared in participants' accounts of support. Specifically, the principles of independence, dependence and mutuality will be identified. In discussion, it will be argued that these principles bear striking affinities with the concept of 'possessive individualism' – a perspective within socio-political theory which critiques the constitution of individualism within liberal democratic society. These issues will be considered in terms of their consequences for social resources and the experience of illness.

The final chapter of this thesis takes the form of a discussion, and will draw together the various themes which will have been addressed within this thesis. This chapter will identify the implications of this thesis for social science and health research, and will outline the

specific contribution of this thesis to knowledge. Finally, this chapter will identify prospective topics for future research.

Chapter Two: Literature review

2.1 Introduction

This study aims to investigate how people living with multimorbidity experience multiple concurrent illnesses as meaningful, and also how these people experience the receipt of support and assistance from other people.

The first part of this chapter will introduce the concept of multimorbidity as a nascent population health concern and as a challenge to existing structures of healthcare organisation. Literature will be presented from epidemiology, health economics, and health services research, and the ways in which multimorbidity has been addressed within policy will be detailed. Following this, literature pertaining to the lay experience of multimorbidity will be introduced. Here, literature will be drawn from social science, and particularly qualitative research.

This review will then address the issue of social resources which is taken to mean the 'physical and emotional sustenance' provided by others during illness (Corbin and Strauss, 1988; 109).² Literature will be introduced from a range of disciplines including social epidemiology, social policy, and medical sociology.

In concluding this chapter it will be argued that the lay experience of multimorbidity has been researched only in a narrow sense and requires further attention. Further, the experience of support and assistance within this patient population has been largely neglected. Research questions will be established in recognition of the gaps in knowledge.

² The term 'social resources' has been used variously by authors from diverse social scientific fields: in particular by Corbin and Strauss (1988) and Lin, Vaughn and Ensel (1981).

2.2 The challenge of multimorbidity

The prevalence and costs associated with multimorbidity mean that it is now recognised as a fundamental challenge to existing models of healthcare organisation (Mercer et al., 2009). The following section details the evidence base supporting this assertion, and outlines some of the ways by which multimorbidity is beginning to shape health policy and practice.

2.2.1 Prevalence, costs and outcomes

Understanding the scale of the challenge posed by multimorbidity as a population health issue is not a straightforward task. The epidemiology of multimorbidity is itself an emergent field and as such there remains a good deal of inconsistency in terms of how multimorbidity is conceptualised, operationalised, and measured. Furthermore, the variety of methodological models employed across epidemiological studies makes comparison of findings problematic.

Identifying prevalence estimates of multimorbidity is itself a difficult task, and one that continues to push advances in the field of epidemiology. Within epidemiological literature, multimorbidity is generally taken to mean the 'co-existence of two or more long-term conditions in an individual' (Mercer et al., 2009).³ However, within this definition there is sufficient ambiguity to allow for multimorbidity to be operationalised in a number of different ways. By way of illustration, Salisbury et al. (2011) define multimorbidity as 'multiple coexisting chronic medical conditions' and within this definition investigate two different operational models of multimorbidity. Firstly, multimorbidity measured as the presence of one or more chronic illnesses from the 17 chronic illnesses incentivised by the Quality and Outcomes Framework (QOF). Secondly, multimorbidity defined as the presence of one or more chronic illness from an extended list of chronic illnesses as

³ This definition has also been applied in this study, specifically in terms of defining the sampling framework

detailed within the Johns Hopkins University Adjusted Clinical Groups (ACG*) Case-Mix System (the ACG/EDC approach). Both of these operational variants measure multimorbidity as 'multiple chronic conditions'. However, across both measures of multimorbidity, the authors report prevalence as varying greatly – 14% using QOF multimorbidity and 56% using ACG/EDC approach. This disparity in prevalence is illustrative of the variety of prevalence figures generated by the wider epidemiological literature. Schneider et al. (2009), for example, report a prevalence of > 1 chronic condition as 12.7%, (this study calculated multimorbidity based upon an inclusion criteria of just 6 chronic conditions). In stark comparison, Schram et al. (2008) report multimorbidity prevalence of 72% (this based upon inclusion criteria of 185 chronic conditions derived from the International Classification of Diseases (ICD)). A recent systematic review of multimorbidity prevalence in primary care (Fortin 2012) found just two prevalence studies specific to UK primary care. Prevalence of multimorbidity in these studies was estimated at between 49% (Macleod et al., 2004) and 81% (Kadam et al., 2007). In recognition of these issues, the international epidemiological community has taken the standardisation in definition and measurement of multimorbidity to be a primary focus of its attention (Goodman et al., 2013; Mercer et al., 2009), and epidemiological studies continue to research multimorbidity prevalence across various populations.

Beyond prevalence studies, epidemiological literature has also investigated associations between multimorbidity, patient outcomes, and service resource utilisation. In this regard, multimorbidity is associated with increased mortality rates (Gijsen et al., 2001; Menotti et al., 2001; Landi et al., 2010), and is inversely related to health related quality of life (HRQOL). A systematic review into multimorbidity and HRQOL among patients in primary care (Fortin et al., 2004) identified this inverse relationship across a range of studies, with multimorbidity threatening to impact negatively across all dimensions of HRQOL. The authors also point out that existing studies have demonstrated this inverse relationship more clearly demonstrated in relation to the physical components of HRQOL, and that

social and psychological components remain under-researched. It should also be noted that epidemiological research into HRQOL relies almost exclusively upon the Short-Form-36 Health Survey (SF-36) and Short-Form-20 Health Survey (SF-20) instruments, and this poses some clear conceptual limitations upon this research (Guyatt, 1997). In more focused studies of patient outcomes, multimorbidity has been shown to affect physical functioning negatively (Bayliss et al., 2004; Rijken et al., 2005; McDaid et al., 2013; Lawson et al., 2013), to limit social and domestic participation (Wilkie et al., 2013), and has also been associated with depression (Gunn et al., 2012; Spangenberg et al., 2011) and psychological distress (Fortin et al., 2006).

In terms of the economic costs of multimorbidity, a large number of studies have identified multimorbidity as a major source of expenditure within health care systems which are oriented towards a single disease model of illness (Fortin, 2005). Multimorbidity has been shown to be a valid predictor of hospital inpatient costs (Friedman et al., 2006) and is associated with both unplanned admissions to hospital (Payne et al., 2013) and increased length of hospitalisation (Bergeron et al., 2005). People living with multimorbidity are more likely to consult their doctor (Schneider et al., 2009; Starfield et al., 2005), and costs associated with prescribed medications also increase with multimorbidity (Nagl et al., 2012; Ramage-Morin, 2009). More generally, studies into the total costs of healthcare provision identify that the costs of general healthcare increase dramatically among people living with more than one chronic illness (Glynn et al., 2011; Fishman and Von Korff, 1997).

The weight of evidence now linking multimorbidity to both adverse patient outcomes and increased economic costs has resulted in multimorbidity being identified as one of the more pressing challenges to contemporary health care delivery.

2.2.2 Meeting the challenge of multimorbidity

In recent years, health care professionals (HCPs), researchers, and policy makers have begun to take steps towards meeting the challenges posed by multimorbidity.

At the forefront of such efforts have been critiques of clinical guidelines (CGs). Despite the aforementioned evidence linking multimorbidity with adverse outcomes, CGs in the UK continue to be structured around a single disease model of illness (Guthrie et al., 2012; Hughes, McMurdo, and Guthrie, 2013). The rationale for single disease guidelines is increasingly being questioned by researchers and policy professionals working within the field of multimorbidity research. Evidence exists to suggest that the implementation of existing CGs may be detrimental to the care of people with multimorbidity (Boyd et al., 2005). In particular, strict adherence to clinical guidelines has been associated with undesirable and potentially harmful polypharmacy (May, Montori, and Mair, 2009; Guthrie et al., 2011). A further line of criticism concerns the evidence base for CGs, and the fact that clinical trials often exclude potential participants with co-morbidities in the interest of maintaining sample homogeneity. The outcome of this tendency is, of course, that clinical trials often do not take account of people living with more than one chronic condition (Fortin, 2006). Hughes et al., (2013) have identified the single disease focus of clinical trials as a key driver in shaping the single disease focus of CGs.

In recognition of these issues, there have been calls for CGs to take account of multimorbidity. Hughes et al. (2013) call for CGs to cross-reference one another systematically, to include specific common multimorbid vignettes, and for a change in the ways that CGs are evidenced. Recent commentaries have also called for increased emphasis upon the role of clinical judgement and patient preferences, and for clinical guidelines to be considered heuristic aids, rather than statutory regulation (Guthrie et al., 2012). However, despite tentative recognition of these issues by the National Institute for Health and Care Excellence (NICE, 2012; Haslam, 2014), CGs continue to assume a single disease model of illness.

In terms of UK primary care, there have been growing calls for general practice to take account of the realities of caring for patients with multimorbidity. Kadam (2012) notes particular challenges posed to GPs by multimorbidity and identifies three lines of associated work: i) the weight of clinical information needed to be collected, ii) the need for flexibility in terms of care planning as conditions progress, and iii) the challenge of communicating with other services and across disciplines in patient management. The author identifies that the recommended 10 minute general practice consultation is an unrealistic timeframe within which to accomplish this work, and does not facilitate best practice in caring for patients with multimorbidity.

More recently, academic research has sought to address the challenge of multimorbidity through the design and implementation of interventions geared towards improving patient outcomes, and reducing service utilisation and costs. A recent systematic review (Smith et al., 2012) has mapped out the design and scope of such interventions, and reported that interventions tend to address the organisational structure of care delivery, case management and interdisciplinary team working. The authors identify the results of such interventions as mixed, but note the potential for interventions to improve practices of prescribing among HCPs and medication adherence among patients. The authors further consider the apparent difficulty in improving outcomes among patients with multimorbidity, and suggest that that a focus upon particular risk factors or functional difficulties may be a more effective basis for intervention. In general, however, the efficacy of such interventions is mixed, and the evidence base supporting multimorbidity interventions is limited.

2.3 Qualitative studies of multimorbidity

In light of the above evidence, the past decade has witnessed an increasing number of qualitative studies addressing the issue of multimorbidity from a patient perspective. It should be noted, however, that while this body of literature continues to grow it remains

limited in scale and scope. The following sections consider the conceptual scope of this literature and the role of self-management policy as a driver of this research.

2.3.1 Multimorbidity and self-management research

Existing literature concerning the patient experience of multimorbidity has been shaped, to a large degree, by wider policy imperatives concerning the management of long-term conditions in primary care. In particular, the drive towards patient self-management as a means of chronic illness management has directed the focus of qualitative studies towards the ways in which people with multimorbidity self-manage their illnesses. In recognition of this, before progressing to review this literature directly, it is worthwhile to consider the emergence of self-management and the ways by which self-management policy has shaped qualitative literature more generally.

Self-management has been central to NHS long-term condition strategy since the late 1990s and proponents regard self-management as advantageous in two distinct ways. Firstly, self-management is considered a means of involving patients and wider family members in issues of choice and decision making – this is understood in both practical and ethical terms as a superior mode of healthcare delivery. Secondly, self-management is seen as a mode of health care delivery which is less costly, and as means of working towards easing the financial pressures posed by an ageing population living with increasing levels of chronic illness. These tenets have been subject to a number of trenchant critiques which question both the political impetus behind self-management and also its underlying evidence base (Bury and Taylor, 2007; Kendall and Rogers, 2007; Kendall et al., 2011). However, despite such criticism, self-management continues to be a defining principle in the organisation and delivery of health care in the UK (DOH, 2013).

While any further review or critique of self-management policy is beyond the scope of this thesis, it is important to recognise the conceptual and theoretical influence that self-management exerts in related qualitative literature. This issue is particularly pertinent

once we recognise the influence of psychological models of agency and action in self-management literature. For example, Ong et al. (2014) have charted the role of psychological models in mapping out the relationship between the concept of 'behaviour change' and self-management interventions. The authors consider the dominance of psychological models of behaviour to be problematic, particularly with regards to the privileging of cognitive theories of the individual. As the authors note: 'The rise of cognitive approaches to understanding behaviour and emotion have increasingly focused interest and behaviour change technologies on the intra-psychic processes of belief and attitude formation, cognitive styles and mental models' (Ong et al., 2014). This, the authors argue, should be met by an affirmation of the role of the social, with self-management being recognised as an inherently social practice. Similar issues concerning the influence of 'health behaviourism' have elsewhere been outlined in genealogical fashion (Armstrong 2009). Armstrong traces the concept of health behaviour, highlighting that in recent years the concept of health behaviour has been influenced heavily by psychological and micro-economic theory. Armstrong relates this to the emergence (within health research) of an understanding of patient agency as the 'self-appraising patient' who 'increasingly (makes) autonomous choices about whether or not to act in the name of health' (Armstrong, 2009: 291).

The implications of these issues for this thesis are twofold. Firstly, it should be recognised that the development of the field of qualitative multimorbidity research has been shaped by wider policy drivers geared towards illness self-management. Secondly, given the potential association between self-management and cognitive / behavioural models of agency (Cohn, 2014; Ong et al., 2014), multimorbidity self-management literature should be considered critically in terms of the assumptions made about individual agency, and the extent to which social and cultural factors are recognised as shaping self-management practices.

2.3.2 Multimorbidity and illness prioritisation

As has already been suggested, the majority of qualitative studies to address multimorbidity have done so in terms of illness self-management. The following section outlines this literature to date.

Early literature in the direction of multimorbidity self-management identified that multimorbidity is often accompanied by complex and demanding medication regimens (Townsend, Hunt, and Wyke, 2003; Townsend, 2005). However, perhaps the most significant early contribution was that made by Bayliss et al. (2003), who highlighted the potential complexity of multimorbidity self-management, in addition to a number of 'barriers' to self-management (including social, environmental, and economic difficulties). Most significant, however, was the authors' observation that approximately half their sample 'cited a single dominant condition as an impediment to the care of other conditions' (Bayliss et al., 2003:19). The authors also noted, however, that 'There was no pattern to these dominant conditions' (Bayliss et al., 2003: 19). This observation – that lay individuals recognise a particular condition to be 'dominant' – has endured within much of the subsequent literature, and latter studies have taken up the challenge of identifying apparently elusive patterns to patients' 'priorities' within multimorbidity.

Illness prioritisation is premised upon the assumption that people living with multimorbidity are faced with competing condition specific claims towards their time, their energy and their social resources. As a result of these demands, it is argued that people with multimorbidity prioritise the self-management of particular conditions or symptoms, often at the expense of others. While the literature in this direction is limited, there exists some variation in how prioritisation is understood to work in practice.

Schoenberg et al. (2009) argue that prioritisation in multimorbidity should be understood as the ways in which resources (including time, money and informal support) are spent upon particular conditions. Prioritisation in this sense is conceived as a 'strategic choice' made by the individual with multimorbidity who aims towards the maximisation of health

and well-being. Accordingly, the authors describe the 'strategic accommodation of multimorbidity' to include:

...allotting a great deal of time to self-care activities, figuring out ways to pay for expensive treatments, and, even without drawing on many informal networks, juggling these numerous and complex combinations of chronic illnesses (Schoenberg et al., 2009:10).

The authors continue to identify that such strategies are informed by two issues: the individual's knowledge of particular condition severity, and the potential of conditions to cause disability. While these are useful observations, this insight remains somewhat underdeveloped. The authors provide no explanation as to the form and content of condition specific knowledge, nor is the notion of the 'potential to cause disability' explored in any depth. Further, the authors assume some form of causal link between these factors and specific self-management 'strategies'; the article does not develop a sufficient discussion as to how such a process should be understood.

Similar psychologically-informed studies into illness prioritisation include that of Mc Sharry et al. (2013). This study involved people living with depression and diabetes, and the authors report that participants' 'cognitive representations' of these conditions affect self-management priorities. While useful in a descriptive fashion, the insight afforded by this study appears to be limited by its reliance upon a cognitive model of agency, and does not sufficiently explore the relationship between 'cognitive representations', lay priorities, and self-management practices set in a social context. Similarly, Elliot et al. (2007) identify medication self-management as a key site of patient prioritisation, and suggest that prioritisation is linked to individuals' perceptions of medication efficacy and future risk of disease. Here again, useful insight is provided into how people with illness interpret medication efficacy and the concept of risk. However, the reliance upon psychological and cognitive models of agency limit the scope of this insight – the authors regret, for instance,

that they are unable to identify 'adherent personalities' among participants with multimorbidity.

In contrast to psychological perspectives, Lindsay (2009) suggests that illness prioritisation should be understood as a dynamic process in which social context is key. In accordance with Bayliss et al. (2003), Lindsay (2009) observes that people with the same combination of conditions often understand illness priorities differently. A number of influences upon illness prioritisation are identified, which include: the unpredictable nature of the disease, conditions which are not controlled by medication, and conditions that 'set off' other conditions (Lindsay, 2009: 994). The author also suggests that prioritisation is likely to be a dynamic process informed, primarily, by lay and cultural frameworks of knowledge. The authors suggest the importance of biography in shaping individual perceptions of priorities; however, it is also reported that Bury's (1982) concept of biographical disruption does not account for the complexities of multimorbidity illness trajectory and biography.

Morris et al. (2011) present a similar reading of illness prioritisation as a dynamic and deliberative process. The authors coin the process one of 'shifting priorities' wherein individuals' priorities change according to a number of factors. The authors identify significant factors such as: 'timing between diagnoses, prior experiences, recommended self-management activities, bereavement, contact with health services and flare-up of conditions' (Morris et al., 2011:153). The model of 'shifting priorities' is designed to perceive of the transitory nature of prioritisation as something which is continually re-evaluated and re-organised. The dynamic nature of prioritisation has been further emphasised by Cheraghi-Sohi et al. (2013) who suggest that illnesses priorities shift according to social context, clinical interactions, and the ability to control symptoms. The authors also sound a cautionary note in terms of the previously assumed link between illness priorities and self-management practices, suggesting that the relationship between illness priorities and self-management practice is complicated by the burden of illness and

perceived antagonisms between condition-specific self-management practices. This insight challenges the previously assumed link between illness priorities and specific self-management practices (although this is not stated explicitly by the authors).

The notion of prioritisation is further complicated in an important contribution by Pickard and Rogers (2012). Here the authors emphasise what they consider to be an epistemic rift between the concept of self-management (underpinned by biomedical knowledge), and lay knowledge. In contrast to a normative model of self-management, the authors present a phenomenologically informed critique which argues for multimorbidity self-management to be understood in terms of embodied knowledge – a form of lay knowledge which the authors consider at odds with the ‘abstract, rational model of patient knowledge assumed in programmes like the EPP ’ (Pickard and Rogers, 2012:16). The authors inject a sense of epistemic doubt into earlier readings of multimorbidity self-management, and question the frameworks of knowledge which are presumed to inform lay agency or ‘behaviour’ in primary care self-management literature.

A similar challenge to the rational model of self-management in multimorbidity is provided by Hurd Clarke and Bennett (2012) who contend that individuals with multimorbidity not only manage the practicalities of illness, but also attend to self-management in moral terms. Accordingly, it is argued that individuals with multimorbidity work towards the ‘moral responsibility’ of preventing additional chronic conditions and functional loss (Hurd Clarke and Bennett, 2012:14). This perspective further emphasises the place of exogenous frameworks of sense making (in this instance morality) which shape lay meaning. An appreciation of such factors offers the potential for more insightful interpretations of prioritisation in multimorbidity.

A final challenge to the rationalised model of multimorbidity self-management is delivered by Townsend (2012) who applies an interpretation of Bourdieu’s theory of practice to the patient experience. Townsend presents the individual living with multimorbidity as located

within social and cultural schemes (adopting the motifs of habitus and field). While this paper does not add to the author's earlier publications in describing the practicalities of living with multimorbidity (see Townsend, 2006), it makes an important contribution in terms of questioning the ways in which individuals understand and manage concurrent conditions, and in emphasising the role of culture in shaping these practices.

In summarising the existing qualitative literature concerning multimorbidity, the influence of self-management policy as a driver of research is clear. The majority of qualitative literature addressing multimorbidity takes up the issue of how people manage concurrent conditions, and 'illness prioritisation' has emerged as the leading explanatory model. Within this literature there exists significant variety in terms of the theoretical approaches applied to self-management and prioritisation. The most insightful and illuminating literature is found in studies grounded in medical sociology. Recent contributions from sociological literature have begun to develop earlier empirical observations about the complexity of multimorbidity (Pickard and Rogers, 2012; Hurd Clarke and Bennett, 2012; Townsend, 2012). These contributions employ various models of the individual agency and social action which are grounded in theories of social practice (Ortner, 1984). However, this literature remains limited to a handful of empirical studies, and more research is needed to discern the lay meaning of multimorbidity: how lay meaning shapes attitudes towards illness management, and how these issues are experienced in particular combinations of chronic illnesses.

2.4 Social resources and health

Of primary concern to this thesis is to explore how people living with multimorbidity experience the receipt of support and assistance as meaningful. The following sections take up this issue, and consider the place of social resources in emerging models of health care organisation and delivery, the various disciplinary approaches towards

conceptualising social resources and health, and the ways in which medical sociology has addressed social resources in chronic illness literature.⁴

2.4.1 Social resources in health policy and practice

In recent years, the theme of social resources has assumed an increasingly prominent role in UK health and social care policy and practice. The following section details some of the ways in which social resources have been incorporated at the levels of policy, health care organisation, and primary care practice.

At the level of government policy, social resources are apparent in the UK coalition government's White Paper 'Vision for adult social care: capable communities and active citizens' (Department of Health [DH], 2010). This document provides a clear indication as to the role envisaged for social resources in future UK health and social care policy. According to this document, social care is no longer to be understood as 'solely the responsibility of the state', but rather 'Communities and wider civil society must be set free to run innovative local schemes and build local networks of support' (DH, 2010: 4). Throughout this document, emphasis is placed upon the notion that individuals are not isolated consumers of care, but rather, are connected members of social groups. These social groups are understood in terms of their capacity to affect the care and outcomes of individuals. Individuals are conceived as 'active citizens' rather than passive recipients of care, and 'capable communities' as a source of potential resources. Throughout this document, the concepts of social support, social networks and social capital are deployed regularly, with (often oblique) reference to social epidemiology and sociological theory as an evidence base. This policy strategy may be located within a wider political narrative which questions the role of the state (as a traditional provider of care), and as part of a trend whereby the status of care providers is extended towards non-state agents and

⁴ To date, no study exists to the author's knowledge which addresses social resources and multimorbidity directly – insight will therefore be drawn from wider literature addressing chronic illness.

agencies, voluntary and community groups, and informal carers. This policy trend has been subject to a range of critiques with regards to underlying socio-political theory (Kisby, 2010; Levitas, 2012; Sage 2012); however, while important, such criticisms are beyond the remit of this review. It is sufficient for the purposes of this thesis to recognise that social resources – through concepts such as community and social networks – are increasingly apparent in policy discourse, particularly in relation to the design of services and care provision.

At a slightly less nebulous level, social resources are also apparent in emerging models of healthcare service organisation such as in the ‘asset-based approach’ to healthcare. Asset-based approaches seek to identify individual and community resources or ‘assets’ which may be built upon in order to affect health outcomes. Such approaches have their origins in community development theory which, during the 1990s, moved away from conceptualisations of community in terms of a deficits model, and towards an approach which considered the potential of community assets (Kretzmann and McKnight, 1996). When applied to health care, proponents of an asset-based approach argue that it:

... makes visible and values the skills, knowledge, connections and potential in a community. It promotes capacity, connectedness and social capital (McLean, 2011: 2).

Here, as in the above White Paper, concepts from sociological literature are deployed – community, social connectedness, social capital. The most widely invoked concept in this literature is that of social capital (the implications of this will be addressed later in this thesis). Asset-based approaches to healthcare are increasingly apparent in the UK, and may be seen in examples such as the ‘capable communities’ programme of public service reform (IPPR, 2010), and in the public health strategy of NHS Scotland (Burns, 2011). As an indication of the enthusiasm and optimism which has accompanied asset-based

approaches to health, we need look no further than a recent endorsement from Sir Michael Marmot:

The health and wellbeing of people is heavily influenced by their local community and social networks. Those networks and greater social capital provide a source of resilience. The extent to which people can participate and have control over their lives makes a critical contribution to psychosocial wellbeing and to health. Taking an asset-based approach at a local level fosters greater local confidence and self-esteem for people and communities (Marmot, in Foot, 2012: 3).

Here again, the influence of sociological and social epidemiological theory and research is clear: social networks and social capital provide a requisite theoretical foundation. The influence of social science in this respect reflects what Blaxter (2004) has termed the 'socio-biologic transition', or the adoption of sociological and psychological theory and method in the wider corpus of biomedicine. However, despite widespread endorsements from policy makers and population health experts, the asset-based approach has received criticism. Friedli (2012), for example, posits that asset-based approaches are less concerned with the progressive delivery of health and social care, but rather 'sound the drum beat for the retreat of statutory, state provision of both public health services and public health' (Friedli, 2012: 10). It should also be added that the association between communitarian and neo-liberal theory (in policies of community and citizenship) has elsewhere been considered a strategy of population management within the sociological critique of governmentality (Houdt and Schinkel, 2013). However, further consideration of these critiques is beyond the scope of this review.

At a more localised level, individuals' social and community networks are increasingly recognised as a resource in primary care. In particular, the emergent concept of 'social prescribing' incorporates much of the wider literature concerning social networks, social capital and health assets. Social prescribing is presented as a means of extending the

capabilities of general practice and primary care beyond a singularly biomedical focus, and towards a more holistic model of prescribing patients those ‘assets’ located in the community. According to Brandling and House, familiar examples of social prescribing include:

... voluntary work agencies, further education, libraries, social or lunch groups, self-help groups, befriending organisations, hobby clubs, horticulture, sports clubs, nature conservation, book groups, art or dance classes (Brandling and House, 2009: 454).

Social prescribing is a recent development in terms of health policy and service design, and the related literature is limited. However, social prescribing is now actively being incorporated into primary care intervention studies (Blickem et al., 2013).⁵ Proponents of social prescribing have begun to argue for its benefits in terms of patient outcomes (Horne, Khan, and Corrigan, 2013) and also the promise of efficiency savings (National Endowment for Science, Technology and the Arts [NESTA], 2013). In light of these factors, social prescribing is likely to continue to garner attention and enthusiasm. It might be added, however, that through sharing a common theoretical and evidential basis as the aforementioned ‘asset-based’ perspective, social prescribing is liable to be subject to similar critiques in terms of underlying political and economic drivers.

2.4.2 Epidemiological foundations and psychological ‘mechanisms’

Much of the foregoing discussion into social resources and health is founded upon social scientific research from social epidemiology, psychology and sociology. The following section outlines the main concepts and themes from social epidemiology and psychological literature, before progressing towards a more focussed discussion of perspectives from medical sociology.

⁵ The results of this trial have yet to be published.

The association between social relationships, social integration and health is long established. In his seminal text *Suicide* (1999) Durkheim demonstrated statistical associations between social integration and rates of mortality through suicide. Durkheim's legacy is apparent not only in sociology, but also in social epidemiology where *Suicide* remains a foundational text. Despite Durkheim's pioneering contribution, the association between social connectivity and health remained largely neglected until the late 1970s when the Alameda County Study (Berkman and Syme, 1979) again focused epidemiological attention upon social connectedness. Berkman and Syme (1979) investigated the relationship between social and community ties and mortality using a large-scale prospective study design. This study found that participants who reported a lack of social ties at baseline were between 1.9 and 3.1 times more likely to die by the 9-year follow-up point. Following the Alameda County Study, similar findings have been reported across a variety of studies from a range of countries (House et al., 1982; Schoenbach, 1986; Orth-Gomer et al., 1988; Kaplan et al., 1988). By the end of the 1980s, the weight of evidence linking social connectedness to health was likened to the degree of evidence linking smoking to ill-health at the time of the 1964 U.S. Surgeon General's report (House et al., 1988).

Developing alongside this epidemiological research have been attempts to explain – through recourse to psychological mechanisms – the pathways through which social relationships affect health. Broadly speaking, two theoretical models dominate this literature: the 'stress-buffering' and 'main effect' models of social support (Barrera, 1986; Cohen and Wills, 1984). The stress-buffering model conceives of a linear causal process between stressful events and health outcomes, with social support acting as a mediating factor. This model theorises an internalised psychological response – the individual's appraisal of stressful events – as the point of influence for social support. Individual appraisal of support is understood to affect cognitive and emotional responses, which, in

turn, are causally linked to health outcomes through psychological and behavioural responses.

By contrast, the main effect model considers social support to be effective independently of acutely stressful episodes. According to this model, social support affects health outcomes through multiple processes: as the source of social influence, enabling access to services and information, and affective in terms of psychological states. The main effect model may be considered to be closer to a sociological reading of social support in that it begins to incorporate factors such as social influence and the provision of support and information as social resources.

Both the main effect and the stress-buffering models have been shown to be theoretically and empirically fallible, and the pathways through which social relationships affect health continue to be the subject of research across psychological sub-disciplines (Uchino, 2006), as well as in contemporary social epidemiology (Kawachi, Subramanian, and Kim, 2008). To date, there remains no consensus as to the specific pathways through which social connections mediate individual health outcomes (Frohlich, 2014).

2.4.3 Social support, social networks and social capital

Beyond social epidemiological and psychological contributions, the concepts of social networks, social capital, and social support have been addressed widely within sociological research. This section outlines some of the more definitive approaches within this tradition, before returning to a more focused discussion of these concepts in terms of chronic illness.

Social support has been conceptualised, typically, as the actions and functions performed for individuals by others (Thoits, 2011), and this has been the subject of significant research. Within this research, an enduring aim has been to delimit the experience of support into various empirically-based typologies. In this regard, the most widely invoked typology of social support continues to be that provided by House (1981) which identifies

social support as comprised of emotional, appraisal, informational, and instrumental assistance. According to Thoits, emotional support refers to demonstrations of love and care, esteem and value, encouragement and sympathy; informational support relates to the provision of facts or advice that may help a person solve problems; while instrumental support relates to the supply of behavioural or material assistance with practical tasks or problems (Thoits, 2011: 146).

A distinct but related concern within social research has been to describe and map the structure and composition of individuals' social networks. Historically speaking, this literature has developed out of an earlier tradition within British social anthropology (The Manchester school of social anthropology) (Barnes, 1954; Bott, 1957). Today, social network literature seeks to map the structure (inter-relationships, frequency of contact, types of relationships) of social networks, and relates this to the availability and quality of support. Archetypal studies include Antonucci and Akiyama's (1987) *Social networks in adult life*, and Wellman's (1990) *Families in community settings*. However, in the UK, the most influential studies have been those carried out by Clare Wenger in relation to the social networks of older people in urban and rural communities. In an approach similar to that adopted by House in relation to social support (1981), Wenger has established typologies of social networks based upon characteristics such as types of social relationship (filial, friendship etc.) and geographic proximity. Wenger's (1995) typology of social networks among older people consists of five types of social network: local family dependent, locally integrated, local self-contained, wider community focused, and private restricted. Wenger argues that the composition of individuals' social networks owes, largely, to three factors: the availability of local close kin; the level of involvement of family, friends and neighbours; and the level of interaction with the community and voluntary groups (Wenger, 1995).

There are, therefore, two distinct but related traditions within social research: social support literature and social network literature. Some authors have been at pains to stress

the conceptual distinction between social support (understood as the practical, emotional and relational process of supportive acts) and social networks (the form, structure or pattern of social relationships) (Phillipson, 2001). However, in practice, this distinction has never been particularly firm due to the shared conceptual and theoretical ground between both traditions. Further, any distinction between social support and social network literature has become less pronounced as both traditions have come to be subsumed within the unifying concept of social capital throughout the 1990s.

The concept of social capital now represents the dominant theoretical and conceptual perspective concerning social networks and social support within the social sciences. Social capital has unified literature on social support and social networks under a single banner, and continues to inform (theoretically) contemporary research into social connectedness and health. As an indication of the synergy provided by social capital in this respect, Giddens' statement that 'social capital refers to trust networks that individuals can draw on for social support' (Giddens, 2000: 78) highlights the accord between a social network perspective and social support. It should be noted, however, that social capital is not without its critics (see Fine 2008, 2010; Fine and Milonakis 2009 for trenchant commentary and critique regarding the emergence of social capital), and this thesis does not seek to adopt a social capital perspective.⁶ Despite this, social capital's status as the dominant theoretical perspective in much sociological literature, as well as its prominence in policy and service design, means that it demands further attention.

Social capital theory has developed following the contributions of three authors: Pierre Bourdieu, James Coleman, and Robert Putnam. For Bourdieu, social capital is taken to refer to:

⁶ The decision not to adopt a social capital perspective will be developed fully in the Theoretical review chapter of this thesis.

...the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition (Bourdieu, 1986: 248).

Coleman provides a similar theory of social capital 'paralleling the concepts of financial capital, physical capital, and human capital – but embodied in relations among persons.' (Coleman, 1988: 118). According to Coleman, social capital 'exists in the relations among persons. Just as physical capital and human capital facilitate productive activity, social capital does as well' (Coleman, 1988: 101).

Putnam provides a more encompassing definition, suggesting that:

...social capital refers to connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them (Putnam, 2000:19).

Following these definitions, social capital has tended to be operationalised in one of two ways. Firstly, following Bourdieu and Coleman, social capital is conceived as individual-level resources available to the individual by virtue of a social network. Alternatively, social capital is conceived, according to Putnam, as a collective or 'ecological' factor which includes (sometimes confusingly) 'norms of reciprocity' or trust. Under this guise, social capital is conceived to work at various levels of abstraction, beginning at the level of the immediate social network, but also at the level of community, cities and even at the level of nation states. Portes (2000) has made reference to this individual / collective distinction as the 'two meanings of social capital'.⁷

The two meanings of social capital are apparent in the various applications of social capital to health research. As an 'ecological' level factor, social capital has been adopted

⁷ Portes (2000) identifies this semantic distinction as being under-theorized and responsible for a good deal of the theoretical and practical inconsistencies apparent within social capital research.

enthusiastically within social epidemiology and public health literature.⁸ At the individual-level, social capital is apparent as a theoretical motif in studies which seek to explore the role of social relationships and social networks in shaping health related outcomes and behaviour. In this regard, social capital has been applied to studies which seek to explore issues as diverse as: access to health care (Derose and Varda, 2009), the meaning of childlessness at end of life (Wenger, 2009), practices of intergenerational support (Silverstein, Conroy, and Gans, 2012), health aspirations among working class men (Dolan, 2007), and communities of online support (Drentea and Moren-Cross, 2005). Social capital is also employed as a means of focusing upon the particular characteristics of social relationships and social networks; social capital studies have highlighted the significance of sexuality (Cronin and King, 2012), gender (Hodgkin, 2008), and ethnicity (Fiori, Consedine, and Magai, 2008) in defining the relationship between social capital, social networks and health.

2.4.4 Social resources and chronic illness

Within the sociology of health and illness, the themes of social networks and social resources have received attention in the context of chronic illness. Research in this area has considered the role of social networks in the provision of social support, and also the impact of chronic illness upon social relationships. In this sense, the place of family and friends has been considered according to Bury's distinction between meaning as consequence, and meaning as significance (Bury, 1988). Accordingly, the role of family and friends is understood both in terms of the practical and emotional assistance provided

⁸ It is of limited value to address further the epidemiology of social connectedness in relation to social capital. It is of interest, however, to note that many of the earlier social support epidemiologists now publish under the banner of social capital: for example, Lin and Dean (1984) (social support epidemiology) and Lin (2001) (social capital). This issue (and its implication for the efficacy of social capital will be taken up in the Theoretical review chapter).

by others, but also in terms of the impact of illness upon social relationships (which are understood as a key point of identity and selfhood) (Charmaz, 1991; Nettleton, 1995).

Corbin and Strauss (1988) have identified the place of social networks and social resources as essential to the accomplishment of the three lines of illness work (illness work, everyday life work and biographical work). Corbin and Strauss described the concept of social resources as:

A spouse or child to provide physical and emotional sustenance to the ill person and, in turn, someone to sustain the spouse so that he or she can continue to sustain the ill partner... Other resources include someone to drive an ill person to a medical facility for treatment; enough time and energy to perform complicated regimen, such as tube feeding three or four times a day; and the knowledge and skill to carry out procedures such as suctionings, bladder irrigations, and catheter insertions at home (Corbin and Strauss, 1988: 109).

Here there are parallels with studies of social support in that the role of others is taken to include instrumental, emotional, and informational assistance. Corbin and Strauss deliver an account of the role of spouses, family members and friends in accomplishing the 'work' involved in living with chronic illness. In this sense, Corbin and Strauss' contribution is among the foremost sociological studies to demonstrate the role of others in the informal management of illness.

However, practices of support and cooperation during illness have also been identified as problematic for those concerned, and a number of studies have identified supportive relationships as a source of ambiguity and strain:

Families can thus be both a source of practical and emotional support and a source of practical and emotional strain. Indeed, the ambiguities and strains of family life in general are exacerbated with the presence of chronic illness (Nettleton, 1995: 92).

Perhaps the defining characteristic of the sociological contribution (as opposed to the psychological and social epidemiological literature) has been to highlight the complex relationship between the family and social networks as a source of support; the potential for chronic illness to be experienced as uncertainty, suffering and ambiguity; and the place of family and friends in shaping the social and cultural meaning of illness. The sociological contribution is captured in Bury's wider statement as to the meaning of chronic illness:

The experience of chronic illness involves testing structures of support and risking meanings within the practical constraints of home and work. Relationships do not guarantee particular responses, indeed it is the response that shapes the relationships; meanings change as they are tested and altered as they are put at risk. Individuals and their families cannot be entirely sure what the event of such an illness means or will mean for the future; meanings are fashioned in the flux of change, as events unfold (Bury, 1988: 92).

Social networks, therefore, are understood not simply as a resource for the management of illness at home, but are also fundamental in shaping *meaning as significance*. Chronic illness is recognised as posing a threat to previously valued social roles and identities; yet family, friends and loved ones are central to the ways in which this meaning is fashioned and reformed.

A more recent turn within sociological literature has been towards the role of individuals' social networks in terms chronic illness self-management. In line with wider trends of social connectivity and health policy (noted 2.3.1), social networks are identified increasingly as a resource to aid self-management and patient outcomes more generally. This turn is articulated by Rosland and Piette:

As a result of the growing gap between the need for self-care support and existing resources, family members are increasingly recognized as important allies in the care of chronically ill patients, and the last decade has seen a rapid growth of self-

management programmes that include family members (Rosland and Piette, 2010: 8).

The involvement of informal social networks in self-management support accords with the twin principles of delivering more acceptable and efficacious care from a patient perspective, and increased economic efficiency in the management of long-term conditions. A similar perspective is contributed by Vassilev et al. (2010), who identify social networks as central to the ways in which people living with chronic illness self-manage their conditions. The authors argue that self-care should not be understood as the isolated individual engaging in self-management, but must recognise instead the role of community and social networks. In this direction, Rogers et al. (2011) have called for the recognition of social networks and social resources:

The translation and implementation of a self-care agenda in contemporary health and social context needs to acknowledge and incorporate the resources and networks operating in patients' domestic and social environments and everyday lives (Rogers et al., 2011:1).

In a review into the role of family members in self-management, Gallant, Spitze, and Prohaska (2007) note the potential for family members to both facilitate and hinder the efforts of individuals with chronic illness. In summarising findings, the authors identify various ways in which family members affect self-management in a positive sense:

...direct help with medications, offering medication reminders, cooking healthy meals, following a similar diet, monitoring one's diet, accommodating dietary needs, exercising with, playing an active role during doctor's visits, providing transportation to doctor's visits, sharing illness-related information, acting as a liaison with the doctor, talking about shared situations, offering understanding , and motivating older adults to follow their prescribed regimen (Gallant, Spitze, and Prohaska, 2007: 398).

However, in contrast, the authors also identify the various ways that family members might hinder self-management:

Not cooking meals that followed dietary guidelines, following a diet with no restrictions, not accommodating dietary needs, tempting them with forbidden foods, discouraging physical activity, giving unwanted advice, engaging in depressing talk, and not understanding the reality of living with a chronic illness... being (overly) protective (Gallant, Spitze, and Prohaska, 2007: 398).

Here again, there are parallels with earlier studies into social support among older people, and the above self-management practices might easily be incorporated into House's (1981) typology of social support (emotional, appraisal, informational, and instrumental assistance). However, the above contributions demonstrate that social relationships are no simple panacea: social relationships may function in ambivalent, even pernicious ways. Gallant, Spitze, and Prohaska (2007) provide a useful descriptive account of self-management support. However this contribution falls short of delivering a thoroughly sociological account and neglects the more existential concerns apparent in Bury's *meaning as significance* (1988). As with earlier social support literature (and psychologically-informed literature), the treatment of social networks, support and chronic illness appears to lack the critical insight offered by a sociological perspective.

2.5 Conclusion and initial research questions

To date, no study has addressed directly the meaning of social resources from the perspective of people living with multimorbidity. Further, existing literature addressing the lay meaning and experience of multimorbidity is limited in scope. This review has situated this study within the context of literature concerning multimorbidity, and also social resources and health. Accordingly, it is possible to identify a number of areas towards which a study of the lay experience of social resources in multimorbidity will be able to contribute.

Social resources are recognised increasingly as a point of healthcare intervention, and as a means of mediating patient outcomes. This has been shown to be the case at the levels of health and social care policy, healthcare organisation, and in primary care practice. Further, social networks and social resources are also now seen to play an important role in chronic illness self-management: this is being attended to in emerging trials and interventions (Blickem et al., 2013). However, existing studies from a sociological perspective have highlighted the potential for social relationships to be experienced in ambivalent and potentially pernicious ways. As such, it is important to understand how people living with multimorbidity experience the receipt of social resources during illness, and to explore how such supportive practices are considered meaningful by those in receipt of support.

Multimorbidity has been identified as one of the foremost challenges to contemporary healthcare systems. Extant epidemiological literature presents this challenge as one of prevalence, outcomes, and of utilisation costs. In this regard, various measures have been taken to meet the challenges of multimorbidity: the form and function of clinical guidelines have been critiqued, as have models of care oriented towards single diseases. However, research into the lay meaning and experience of multimorbidity remains limited, and further research is needed to address the ways in which illness – particularly concurrent illness – is experienced in a meaningful fashion by lay individuals.

These themes inform two research questions:

- How do people living with multimorbidity make sense of illness and understand their experience of illness as meaningful?
- How do people living with multimorbidity experience social resources, and how is the receipt of support and assistance understood to be meaningful?

These research questions give primacy to lay experience, and recognise the importance of subjective meaning structures in shaping the experience of illness. The following

chapter will detail methodological issues associated with such an approach, and will also outline the structure of this study, the specific methods of data collection used, and the process of analysis which has been applied.

Chapter Three: Methodology and study design

3.1 Introduction

The aim of this thesis is to explore the ways in which people living with multimorbidity make sense of the experience of concurrent conditions, and how the receipt of support and assistance is experienced as meaningful during illness. These issues have been articulated in two primary research questions:

- How do people living with multimorbidity make sense of illness and understand their experience of illness as meaningful?
- How do people living with multimorbidity experience social resources, and how is the receipt of support and assistance understood to be meaningful?

The approach taken by this thesis in answering these questions has been informed by practical and technical factors. However, most influential have been philosophical considerations as to the nature of the social world, and the possibility of attaining knowledge of social phenomena.

The following sections outline the philosophical foundations of this study, before progressing to detail study design and the research methods adopted. It is hoped that in providing this information, the reader will be better positioned to appraise the data chapters which follow.

3.2 Philosophical foundations

Broadly speaking, this thesis may be seen to take an interpretive approach towards social phenomena, coupled with an understanding of the social world as informed by ontological dualism. The following section will outline this perspective.

The application of interpretivist positions within social research has a long and well established history (Bryman, 1988). Interpretive approaches may be defined, in part, through their distinction from naturalist and positivist epistemological approaches in social science. Positivism, simply stated, entails a belief that the methods and procedures associated with the natural sciences may also be applied to the study of social phenomena. Further, it might also be said that positivism considers only those phenomena observable and amenable to the senses as justifiable basis for knowledge. By contrast, an interpretive critique suggests that such a 'scientific' approach fails to take account of the myriad differences between humans (as social beings) and the objects of natural sciences (Bryman, 1988).

A further distinctive feature of interpretivism is its historical association with idealist, rather than materialist philosophy. Put simply, idealism claims that the external world is a creation of the mind. This is not to say that our perceptions of the world are not real, simply that we (the subject) can have no direct access to the world (the object) in any unmediated way. Accordingly, any attempt towards direct one-to-one knowledge of the world as a 'thing-in-itself' is a materialist endeavour, and one which is quite misguided. By contrast, the idealist perspective holds that knowledge of the social world must necessarily involve a focus upon the world as it 'appears' to us in its phenomenal sense.

Following these broad concerns – anti-positivism and idealism – interpretive approaches are summarised by Blaikie (2000) as follows:

Interpretivists are concerned with understanding the social world people have produced and which they reproduce through their continuing activities. This everyday reality consists of the meanings and interpretations given by the social actors to their actions, other people's actions, social situations, and natural and humanly created objects. In short, in order to negotiated their way around the world and make sense of it, social actors have to interpret their activities together, and it is

those meanings, embedded in language, that constitute their social reality (Blaikie, 2000: 115).

An interpretive approach, therefore, is one which affords primacy to lay meaning, language and individual understanding in explaining the social world. This approach is well established within social scientific perspectives on health and illness. The value and necessity of such an approach towards corporal issues is captured well by Johnson, Dandeker, and Ashworth (1984):

Hunger, pain and anger in the human world cannot be described without investigating how individuals use language and symbols to construct what such states mean for them. For it is only by understanding the individual experience of subjective interpretation that we will understand why human beings behave in the way they do; why, for instance, thresholds of pain, attitudes to death and so on, differ so markedly from person to person, and from culture to culture (Johnson, Dandeker, and Ashworth, 1984: 75).

Under the banner of interpretivism there exist numerous distinct perspectives upon how language, meaning, and understanding are conceptualised in relation to the individual and human action. In this regard, increasingly subtle ontological considerations become interconnected with epistemic concerns. This is to say that what we hold to be 'out there' in the social world must inform the modes by which we seek knowledge; as Archer suggests, ontology might be seen as both 'gatekeeper and bouncer' for methodology (Archer, 1995: 22). In light of this, it is important to detail some of the literature which has informed my ontological perspective and which, therefore, has played a role in guiding analysis.

My perspective is informed, in the first instance, by contributions from social phenomenology (Schutz), and to a lesser degree, from ethnomethodology (Garfinkel).

For Schutz, social phenomena are to be 'treated as belonging to a world of objective mind, a world which is, to be sure, intelligible, but not under the form of scientific laws' (Schutz, 1976: 3). Schutz promotes the conceptual apparatus (inherited from Husserl) of the lifeworld : a concept premised upon the belief that individual perspective is shaped by experience, as well as the individual's positioning within natural, social and cultural fields. Accordingly, the lifeworld refers to 'that every day province of reality which the wide-awake and normal adult simply takes for granted in the attitude of common sense.' (Schutz, 1970: 3). Schutz identifies the lifeworld in terms of the historically and experientially derived frames of reference (drawn from the natural world, the social, and the cultural fields) which shape individual perspective. Such frames of reference are to be understood, according to Schutz, as (pre-) biographically accumulated experiences which act as an interpretive or perceptual lens through which the social actor gives meaning to the world. These frames of reference are termed by Schutz (anticipating Bourdieu's concept of habitus) 'habitual reference schema'. Therefore, an awareness of such natural, social and cultural reference schemes is central to the social phenomenological perspective.

A related approach to the 'taken-for-granted' practices of everyday life may be observed in ethnomethodology and epitomised in the work of Garfinkel (1986). Garfinkel (among others) sought to advance social phenomenology through an awareness of the role of linguistic structures and specific context in framing meaning. Within ethnomethodological approaches, there is an emphasis upon the relation between the external world and the subjective realm as bi-directional: in giving an account of an event or a disposition, the individual subject not only gives a phenomenological description, but also plays a role in creating and maintaining social phenomena through the use of language.

In recent decades, a further wave of 'post-interpretive' approaches have taken up the insight offered by ethnomethodology, and have sought to elucidate further the role of

socio-cultural factors in relation to subjective meaning. Such approaches are, in part, a response to a critique of idealism which suggests that to focus upon individual representations of meaning will tend towards introspective or solipsistic accounts of the social – the social world as reduced to the individual's knowledge of it. The following statement from Bourdieu may be read in these terms, and with regard to its implications for interpretive approaches:

...it is good to recall, against certain mechanistic visions of action, that social agents construct social reality, individually and also collectively, we must be careful not to forget, as the interactionists and the ethnomethodologists often do, that they have not constructed the categories they put to work in this work of construction
(Bourdieu and Wacquant, 1992: 10).

This perspective affirms and advances the belief that cognitive structures may not be understood without reference to socio-cultural structures, and is representative of a wider trend within social theory whereby the antinomy of subject and object becomes problematic and even obstructive. For Bourdieu (as for others), any phenomenological account must be approached critically with a view to identifying the ways by which socio-cultural conditions (and power) shape the perceptual frameworks through which the phenomenal world is interpreted.⁹ The implications of this perspective for the social sciences are spelt out by Bourdieu and Wacquant (1992):

A genuine science of human practice cannot be content with merely superimposing a phenomenology on a social topology. It must also elucidate the perceptual and evaluative schemata that agents invest in their everyday life. Where do these schemata (definitions of the situation, typifications, interpretive procedures) come

⁹ In Bourdieu's case, this might be read as the influence of Marxist concerns as to the role of class, and a Webbarian concern for the dynamics of domination.

from, and how do they relate to the external structures of society? (Bourdieu and Wacquant, 1992: 2).

Similar concerns may be observed in the 'structuration' theory of Giddens (1984), or in the 'morphogenic' approach promoted by Archer (1995). In such perspectives, phenomenology alone is treated as insufficient, and there is a drive towards what has been termed 'ontological dualism'. These approaches incorporate, to varying degrees, versions of ontological realism as a necessary adjunct to understanding individual action. Accordingly, the task of social research is to understand the interplay between these positions, the ideal (subjective) and the real (objective). These authors – Bourdieu and Archer in particular – have influenced my analytic perspective, and I would summarise my own position as that of a social phenomenologist seeking to detail the 'every day province of reality' (Schutz, 1970: 3) and to explore the role of socio-cultural structures beyond the individual's experiential and perceptual horizon.

3.3 Background to this study

This study is linked to an existing epidemiological cohort study within the Keele University's ARUK Primary Care Centre – the 2C Study. The 2C study is a prospective study of Osteoarthritis (OA) and Cardiovascular disease (CVD) co-morbidity within a primary care population. The 2C study sample population includes adults aged over 40 years who have a computerised record of clinical diagnosis for both OA and CVD (hypertension, heart disease, and heart failure). Additional morbidities were not treated as a basis for exclusion; therefore additional morbidities were common within this study population. Within the 2C study population, a sub-group of participants consented to be contacted in relation to involvement in additional research. This study sampled from the subgroup of 2C participants who consented to further contact.

Although this study sampled from 2C study participants, this study was not integrated within the 2C study in any way, and was a discrete and independent study. Researchers

involved in the 2C study were not involved in any aspect of research design, data collection, or analysis. One member of the 2C team (Dr James Prior) assisted in extracting the sample from the 2C study dataset.

3.4 Main study design

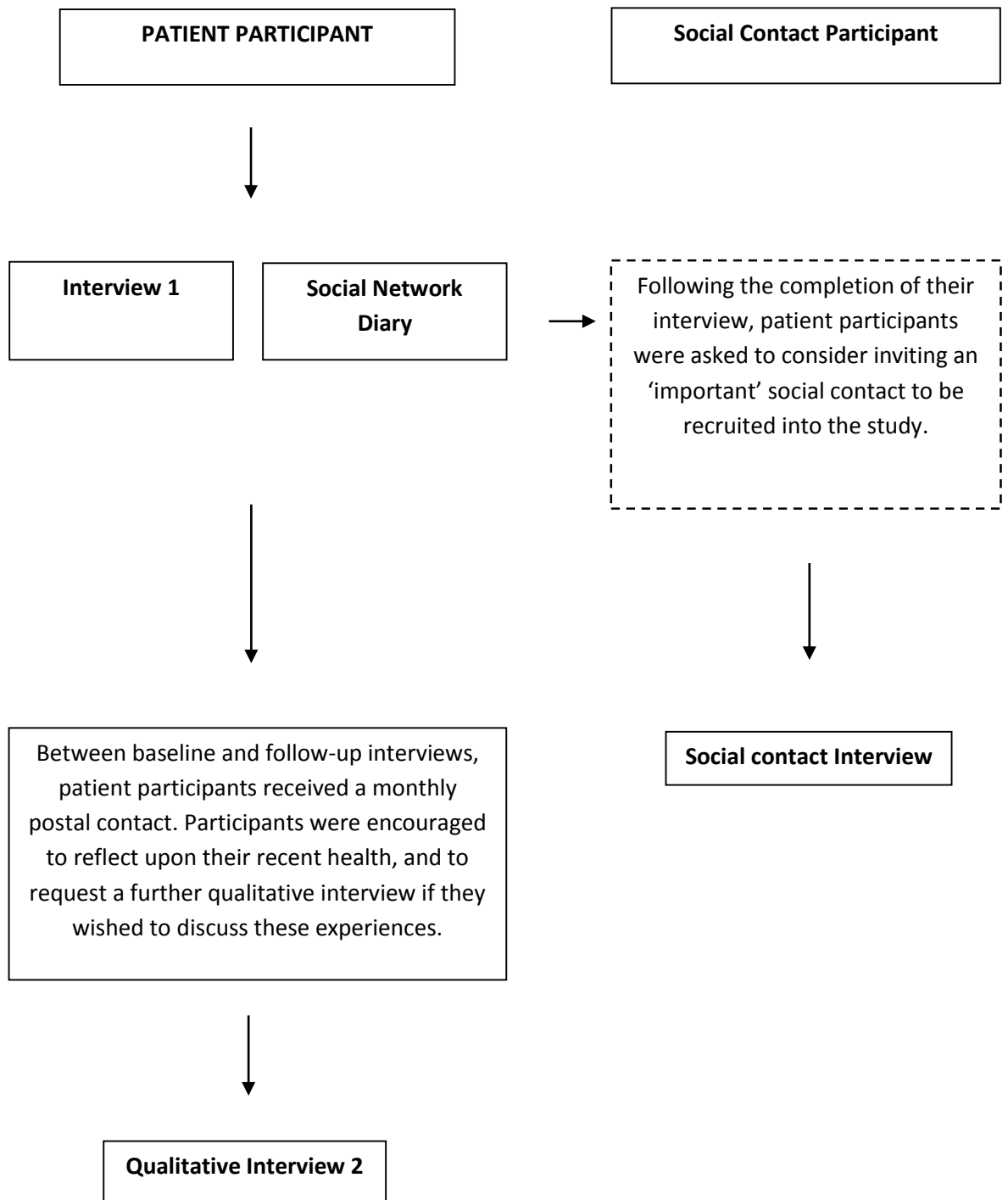
In light of the foregoing philosophical considerations, this study employed a qualitative methodology involving in-depth interviews. The application of qualitative interviewing as a method of data collection is well established within interpretive traditions of health research (Bowling, 2001; Green and Thorogood, 2014), and is consistent with a commitment to the primacy of individual meaning in explaining personal and social worlds.

In consideration of the (above) research questions, this study recruited both patient participants and patient participants' social contacts (friends, family, work colleagues) to participate in qualitative interviews. Patient participants took part in (up to) two qualitative interviews over a three to six month period. Social contact participants took part in a single qualitative interview.

In the time between first and second interviews, patient participants were contacted by post. This contact asked participants to reflect upon their recent health, and provided the opportunity for participants to engage in an additional qualitative interview (see appendix 15). Further, at the time of the first interview, patient participants were given the opportunity to complete a 'Social network diary'. It was envisaged that participants would record the people they were in contact with over a 10 day period, and that this record would aid interview analysis (see appendix 14).

The design of this study and stages of data collection are detailed in following flow diagram (Figure 1) detailed below.

Figure 1 – Study Design Flow Diagram



3.5 Pilot study and Research User Group

A small pilot study was conducted with four members of the Keele ARUK Primary Care Centre's Research User Group (RUG). RUG members were invited on the basis that they were likely to share similar health profiles as the participants in the full study. RUG members all lived with multiple chronic illnesses (including OA), all were over the age of 50, and both male and female RUG members contributed.

Research User Group (RUG) members participated in pilot interviews which focused on issues of multimorbidity and the role of other people in their lives. This process proved to be valuable in helping to refine interview topic guides. For instance, during pilot interviews it became clear that all pilot participants lived with long-term conditions in addition to OA and CVD. It was also apparent that for these participants, the most important or disruptive episodes of illness were often unrelated to the conditions targeted by the research team (i.e. OA and CVD). This discovery influenced the interview schedule used in the initial interviews of the main study; rather than focusing solely upon OA and CVD (the sampling criteria) participant's wider experiences of health and illness were incorporated into the interview schedule. I explained to participants that they had been sampled on the basis of two concurrent conditions, but I also made clear that I was interested in additional conditions or illness episodes, which affected their lives and shaped their relationships with other people. Interviews tended to begin with participants describing and explaining their health in biographical terms with illness being framed by wider life course factors (a process which often led to the identification of additional conditions). This biographical rendering of health and illness shaped the interpretation of multimorbidity put forward by this thesis (see Chapter Four). The emphasis on biography would likely have occurred regardless of the pilot interviews (having emerged within the data), however the pilot interviews meant that initial interviews were better attuned to the ways in which participants understood multimorbidity.

All four RUG members were also approached to complete a social network diary in which they were to record – over a one-week period – the people that they were in contact with. The results of this were mixed. One participant completed the diary with a high degree of detail. However, one participant completed the diary only retrospectively, while the remaining two participants did not complete the diary.

One significant issue to arise from the pilot process was that RUG members did not immediately consider the issue of social networks to be relevant to health issues. One RUG member expressed the belief that questions about social networks were not acceptable in an interview which he understood to be about embodied health. This insight demonstrated that explaining the rationale behind the study – the link between social networks and health – in study literature and face-to-face would be important in ensuring the acceptability of the research to participants.

In addition to the pilot study, the study protocol was presented to a meeting of RUG members (approximately 15 members). The aim of this session was to invite feedback as to the appropriateness of the study design, the study rationale, and study research questions. This was a valuable experience, and helped me to understand how best to present the study to lay individuals. The RUG consultation also provided feedback on study literature, which resulted in a number of minor changes being made (these changes involved improving the readability of study paperwork).

The following sections detail specific and practical aspects of study design, the conduct of interviews, and procedures of analysis.

3.6 Sampling and recruitment

Patient participants

Patient participants were sampled using a purposive sampling frame. The purposive sampling frame was developed by the research team and was used to guide informatics staff in selecting and extracting 2C participant data from the 2C study. Purposive sampling did not involve any personally identifying information. The following section will outline the criteria used to select research participants.

The principal criterion for purposive sampling was that participants should all have received a clinical diagnosis for more than one chronic illness (at least OA and CVD). 2C study data were available for three groups of participants: those with hypertension and OA; coronary heart disease (CHD) and OA; and heart failure and OA. The research team decided to sample participants from each of these groups in equal proportions. The rationale for this being that lay experience of multimorbidity is likely to vary according to the clinical picture of each individual (Bayliss, 2003). In practice, during the course of their interviews, all participants reported additional long term conditions and episodes of illness, which meant that the diagnostic labels used to sample participants (derived from the 2C study) did not reflect their experience of illness particularly well. This being said, the fact remains that the sampling criteria were effective in so far as all participants recruited to the study were people living with multimorbidity. Participant's self-reported chronic and episodic conditions are recorded in Appendix 1.

A further purposive sampling criterion was sex. The decision to sample participants according to sex reflected the likelihood that gender would shape participants' experience of illness and support (Arber and Cooper, 1999; Macintyre, Hunt and Sweeting, 1996). Each batch of participant invitations contained equal numbers of invitations for men and women. This strategy proved effective, and the final study sample contains broadly equal numbers of men and women.

Age was also used as a purposive sampling criterion. Age was an important consideration given the likelihood that age related biographical, social and cultural factors would play a role in individual's experiences of health and illness (Wadsworth, 1997). Initial mail-outs included equal numbers of people from the following age bands: below 65 years of age, 66-75 years of age, over 75 years of age. Subsequent mail-outs were weighted towards age groups with lower recruitment rates in an effort to achieve approximately equal numbers of participants in each age group. In the final sample, however, participants aged below 65 years of age were under-represented (only two participants were under 65). There were several reasons for this underrepresentation; the 2C study contained only a limited number of potential participants aged under 65 who also matched other purposive sampling criteria, and who had agreed to be contacted about future research participation. Further, it is reasonable to speculate that the low recruitment of participants under the age of 65 will have been influenced by the higher proportion of this age group in full or part-time work, and therefore less inclined to engage in a research study which required a prolonged time commitment. As has been stated elsewhere in this thesis, it is important that future research engages with a patient population of younger people living with multimorbidity as this group is likely to face distinct physical, social and economic challenges.

Beyond multimorbidity, sex, and age, opportunities to sample purposively were limited by the data available within the 2C study. It was not possible to sample on the basis of ethnicity or socio-economic demographics. Accordingly, the resulting study sample was homogenous in its ethnic composition – an issue considered in the discussion chapter of this thesis. With regard to socio-economic status, it was possible to approximate participants' economic status through informal discussion (before and after participant interviews) as well as during the interviews themselves. Despite not being able to completely purposively sample participants, the research team were confident that the final study sample would include a participants from a range of different socio-economic

groups. Participants were recruited from six different general practices and the research team (who have extensive experience of the research and management of local healthcare systems) were confident that recruiting participants from these specific general practices would result in a socio-economically diverse sample – this proved to be the case (see Appendix 1). Given that socio-economic status is a principal determinant of health (Marmot and Wilkinson, 2005) it is a strength of this study that different socio-economic groups are represented.

Recruitment followed a batch-mailing format; five batches of 20 study invitations were mailed out to a total of 100 potential participants. Batches of invites were spaced approximately one month apart. The decision to mail in this format was designed to allow for a manageable amount of interviews per month, and also to guard against over-recruitment. Recruitment rates and patterns are detailed in appendix 3. In addition to the 15 fully consenting participants, five individuals responded stating their desire not to consent, four individuals consented to participate but could not be contacted, and two individuals consented but then withdrew once the study was explained in person.

Baseline participants' pseudonyms and details as to whether or not each took part in one or both interviews is detailed in Table 1 (below). Additional participant details (including socio-economic status, self-reported morbidities) are listed in appendix 1. In total 25 interviews were conducted with patient participants, four of these interviews involved a spouse (who were also recruited to participate in the study).

Table 1: Baseline participants by interview

Pseudonym	Sex M/F	Age Group	First Interview	Second Interview	Reason for No Second Interview
Mary	F	65-74	Y	Y	N/a
Ian	M	65-74	Y	Y	N/a
Bill	M	75+	Y	N	Health
Pamela	F	65-74	Y	Y	N/a
Rose	F	75+	Y	Y	N/a
George	M	75+	Y	N	Health
James	M	65-74	Y	N	Health
Theo	M	65-74	Y	Y	N/a
David	M	65-74	Y	Y	N/a
Elaine	F	65-74	Y	Y	N/a
Isla	F	75+	Y	Y	N/a
Mo	F	55-64	Y	N	Bereavement
Judith	F	65-74	Y	N	Unable to contact
Kirsty	F	65-74	Y	Y	N/a
Dan	M	65-74	Y	Y	N/a

Social contact participants

Patient participants' social contacts were sampled through snowball sampling: a secondary non-probability sample accessed through the initial sample (Bryman, 2008).

During discussions before and after interviews, patient participants were asked to consider people who were 'important' in their lives, and whether they would be comfortable in approaching one such person to be invited to participate in the study.

Where patient participants were comfortable with this process, they were invited to distribute a 'study pack' (containing study information literature, researcher contact details, and consent form) to the social contact of their choice. Following this, it was left to the individual in receipt of this information (the social contact) to instigate contact with the researcher.

The decision about whom to invite was led by the patient participant: the only guidance given by the researcher was for the patient participant to consider inviting someone

'important' in their life. It was envisaged that social contact participants would take part in separate interviews; however, in practice, patient participants often stated a preference for involving their social contact in a joint interview. In only one case did the patient participant and the social contact participant request separate interviews. In total, four social contact participants consented to participate in the study.

3.7 In-depth interviews

The decision to use in-depth interviews was made in consideration of the (above) philosophical underpinnings of this thesis. In-depth interviews – and qualitative research more generally – are considered widely as synonymous with interpretive and phenomenological approaches towards social research. The following quotation from Johnson (2002) may be read as an indication of the synergy between philosophy and method:

[In-depth interviewing] begins with commonsense perceptions, explanations, and understandings of some lived cultural experience... and aims to explore the contextual boundaries of that experience or perception, to uncover what is usually hidden from ordinary view or reflection or to penetrate to more reflective understandings about the nature of that experience (Johnson, 2002: 106).

Beyond a philosophical consistency, in-depth interviews were recognised as technically beneficial. In contrast to more structured methods of interviewing, in-depth interviews allow for complexity to be investigated in a more thorough manner, participants' answers may be clarified to a greater extent, and a more relaxed research atmosphere often facilitates the investigation of sensitive topics such as illness (Bowling, 2001: 379).

3.8 Interviews and social network diaries

In terms of the practicalities of interviewing, the types of questions asked of participants conformed, largely, to Patton's (1990) typology:

- Background questions which aim to understand the respondent's previous experiences
- Questions which elicited descriptions of experiences, behaviour, actions and activities
- Opinion or value questions which inform about participants' goals, intentions, desires and values
- Questions about feelings with the intention of understanding emotional responses
- Questions about knowledge and factual information

Interviews were conducted at participants' own homes, and usually lasted approximately 1-2 hours. An interview topic guide was used at each interview. Two broad themes were addressed within this topic guide: firstly, the experience of living with more than one chronic condition, and secondly, the role of other people in participants' lives (see appendix 11). The format of this topic guide developed and was refined as interviews progressed. The adaption of interview topic guides allowed for emergent themes to be investigated in greater depth and detail. The iterative development of interview topic guides is accepted widely as good-practice during in-depth qualitative interviewing (Bryman, 2008; Charmaz, 2006).

All interviews were audio recorded and transcribed following the approach suggested by Reissman (1993). An initial verbatim transcription was produced (by an outsourced company); this transcript was then checked (with any errors corrected) by a process of listening to the interview audio file and correcting any errors in transcription. All transcripts were fully anonymised – pseudonyms were applied to all people, places, institutions and any other personally identifying information.

Interviews with social contacts

Social contacts were invited to take part in interviews about the role they played in the lives of patient participant. As has been stated, in all but one case, social contact participants took part in joint interviews with patient participants.

An interview topic guide was developed for social contact participants (see appendix 12). However, the utility of this topic guide was diminished where joint interviews occurred. In these cases, I was able to blend the topic guides of both patient participant and social contact participant in a way which did not prove to be problematic. In practice, joint interviews felt entirely comfortable and there did not appear to be any difficulties in interview dynamics – all participants seemed comfortable in discussing sensitive topics with both individuals present. This was likely the result of the sampling process, and the fact that in choosing who to invite, patient participants were likely to have chosen people with whom they were comfortable discussing health and issues of a personal or sensitive nature. Despite this, it is quite possible that the presence of a spouse may have shaped the course of joint interviews. However, given the relatively small sample size of participants this may have affected, attempting to detail further this influence would be problematic.

Developing the social network diary

The social network diary was developed following a review of relevant research methods literature, having attended a training course on social network analysis, and through discussion with the research supervision team.

Social network data may be collected by various methods, the suitability of which depends on the type of social networks in question. In recent years, social network analysis has been revolutionised by the advent of digital social networks. Data available via platforms such as Facebook and Twitter represent new and exciting vistas for researchers exploring connections between individuals and larger actors such as corporations or non-

governmental organisations. However, this mode of social network analysis was neither practical nor theoretically consistent with the research questions set out in this study. This study focuses on the meaning of embodied interactions and the role of others in the provision of tangible support and assistance during illness. The real and imagined social networks of single individuals are the object of study, and this type of social network is termed an egocentric network (Wasserman and Faust, 1994).

Three predominant methods for collecting egocentric network data exist. One approach is to observe and record interactions which occur in a given setting and timeframe.

Observation has clear advantages in that the data produced are amenable to quantification and sophisticated quantitative analysis. However observation also requires significant resources in terms of the time (and finances) required to collect data.

Consequently, observation was not considered for this study. A second, and more feasible approach to data collection, is to use a name generator (interview questions about social contacts) such as ‘tell me five people who are important in your life?’. Name generators are easy to administer and require little in the way of resources. However, name generators offer no objective record of interactions and have also been derided within the relevant literature for their reliance on ‘subjective’ or self-reported data. A third approach is to use a social contact diary. Social contact diaries ask participants to record the people they come into contact with over a designated period of time (Wasserman and Faust, 2002). The research team discussed the benefits and limitations of these methods and decided that social contact diaries would be pragmatic (resource efficient) and offer high quality data as they record data on real interactions. This decision was informed by relevant literature. Fu, for example, says that:

With all the characteristics of each contact person, each specific contact and each ego-alter tie on a daily basis, the diary approach reveals every detail of an individual’s actual network. Over time, it can become the most comprehensive and penetrating research instrument for measuring personal networks (Fu, 2005: 184).

Finally, a further factor which informed the decision to employ a social contact diary was that similar qualitative diaries had been used successfully by the supervision team and colleagues in previous studies (Ong and Jinks, 2006, 2009).

Limitations and omission of the social network diary

As has been stated, it was envisaged initially that patient participants would record – over a ten day period – the names of people with whom they came into contact. This record took the form of a ‘social network diary’ (see appendix 14). The rationale for this diary was that it would aid discussion about social contacts during participants’ interviews and would also provide additional data amenable to analysis. However, in practice, this instrument proved to be somewhat ineffectual, and was not widely adopted by participants. A number of participants explained their reasons for not engaging with this part of the study: some felt that the diary involved too great a time-commitment on their part, others considered the act of recording social contacts to be overly intrusive. In practice, only two participants completed the diary, and among these responses, data was partial and incomplete. As a result of these issues, the decision was made, through discussions with the study supervision team, that this component of the study should not feature in either the conduct of interviews, nor in the analysis of qualitative data. Including the two returned diaries would have delivered negligible analytic benefits. A more pressing principle was to maintain a consistent analytic approach across all participants.

Feedback from participants indicated two reasons for the failure of the social contact diary. Firstly, some participants were confused about the purpose of the diary – its relevance to health research – and were unsure about how to complete the diary. Secondly, participants reported that they did not have the time or energy needed to complete the diary. These issues – participant confusion and the burden of completing diaries – are recognised in the relevant research methods literature. Fu (2005, 2007),

among others, has considered the benefits and limitations of social contact diaries; diaries afford rich data, but completing diaries can be laborious, onerous, and are therefore only suitable for highly committed research participants. Indeed, these issues were considered by the research team prior to the implementation of the social contact diary, and efforts were made to simplify the diary's format and to explain its purpose to participants. However, clearly, these efforts were not sufficient, and the social contact diary was not an acceptable component of the study for participants.

The decision to discard the social network diary will have shaped this thesis in a number of ways. Firstly, not collecting systematic and quantifiable data about the composition and structure of participant's social networks means that it is not possible to make causal inferences about the role of these factors in shaping participant's experience of illness and support. Second, as a corollary of this, the study and this thesis are necessarily driven by qualitative data and emphasis is placed upon micro processes of social resource exchange. The consequences of omitting the social contact diary are, therefore, simultaneously strengths and limitations of this study: sacrificing structured and quantifiable data may be regarded as a limitation, however the in-depth qualitative data and theoretical analysis that developed as a result are strengths of this thesis.

Monthly contact

Monthly contact with participants was intended to have three outcomes. First, it was hoped that regular contact would keep participants engaged in the study during the three to six months between first and second interviews. Second, monthly contact enabled participants to inform the research team of any changes in their circumstances and health. Finally, monthly contact gave participants the option of completing additional telephone interviews if they wanted to discuss any changes in their health circumstances. The decision to employ monthly contact was taken following the success of similar methods in

previous research involving the research supervision team (Morden, Jinks, Ong, 2011; Ong, Jinks, Morden, 2011).

In practice, participants did not wish to undertake additional formal interviews. In retrospect, it is likely that asking participants to participate in two interviews, complete social contact diaries, recruit social contacts into the study, as well as engage in additional monthly updates resulted in 'study fatigue' on the part of participants. Participants were enthusiastic and engaged in parts of the study which involved direct contact with a researcher – interviews and the recruitment of social contacts. However, participants did not engage in components of the study which required self-direction – social contact diaries and volunteering for additional interviews. One way to overcome this lack of engagement may have been to increase researcher contact with participants, to remind and to encourage participants. However, no provision was made for additional researcher-participant contact within the NHS research ethics submission, and therefore, further contact was not possible on ethical grounds.

Although participants did not volunteer for additional interviews, some did use the monthly contact to inform the study team about serious deteriorations in their health. Two participants used the monthly contact to indicate that they could not participate in a second interview due to ill health. Other participants used the monthly contact to report stable health, whilst three participants stated that their health had deteriorated but they did not wish to be contacted about these changes. Further, whilst the monthly contact did not result in additional data, informal discussions indicated that participants appreciated this contact as a sign they were still involved in the study. On a personal level, I also feel that keeping in contact with participants throughout the three to six months between first and second interviews aided rapport when it came to conducting the second interview.

3.9 Process of analysis

My analytic approach has been informed by the procedure outlined in Charmaz's (2006, 2008) constructivist grounded theory. Adopting an analytic procedure such as this was helpful in providing structure and consistency in analysis. Further, this approach proved useful in the cross-validation of analysis.¹⁰

Charmaz (2008) describes a constructivist grounded theory approach as one that:

- Begins with an inductive approach
- Involves simultaneous data collection and analysis
- Consists of flexible guidelines
- Emphasises the process of construction in analysis
- Aims towards theories of the middle-range

The following section details the techniques of analysis which are drawn from this perspective.

3.9.1 Coding practices

Process of coding

Constructivist grounded theory (Charmaz 2006) involves of a number of iterative and recursive stages of coding; my approach towards coding was characterised by the following stages.

The first stage of coding was initial coding. Initial coding is characterised by openness on the part of the researcher towards identifying practical and theoretical elements that are present in the data. The specific approach taken in this study was line-by-line coding whereby each line of transcript data is coded initially. Line-by-line coding – although

¹⁰ This framework provided a consistent analytic practice, and aided the supervision team in their critique and validation of the various stages of coding.

labour intensive – promoted an attentiveness to detail, and helped prevent coding from incorporating too many tacit assumptions about the data.

The next stage of coding described by Charmaz is that of focused coding. Focused coding may be understood as increasingly directed and conceptually driven. Following Charmaz (2006), focused coding meant identifying and expanding the most theoretically significant and frequently occurring codes found in initial coding.

Following focused coding, theoretical coding is a final formal coding stage identified by Charmaz (2006). Theoretical coding aims to analyse relationships between categories of codes generated through focused coding. In practice – as is recognised by Charmaz – the distinction between each coding stage was somewhat artificial, and coding was not a linear process. Rather, coding was a genuinely emergent process: concepts would emerge and develop, and initial coding would be revisited and re-coded in light of later theoretical coding.

Coding practices were subjected to a number of stages of review within the study supervision team. Two PhD study supervisors analysed five full interview transcripts independently and developed their own independent coding frameworks; group meetings then addressed similarities and differences between resulting codes. This was an important stage for the refinement of codes and for developing more robust concepts.

Memo writing and free-writing

Memo writing has been identified by Charmaz (2006) as a key intermediary stage between data collection and theory construction. The aim of memo writing is to elaborate (in preliminary fashion) upon categories or codes within data. Specifically, memo writing aims to identify the properties of codes and to define relationships (and identifying gaps) between categories of data. In this study, memo writing was used most productively in the stages between initial coding and focused coding. Memo writing gave space for making

comparisons between data, between data and codes, and between codes and overarching concepts.

Free-writing was also used extensively throughout all stages of coding and was particularly useful in attempting to resolve the tensions and complexities of concepts.

Free-writing is a technique adapted from creative writing and I found the following guidelines to be useful:

- Ideas should be committed to paper as quickly as possible
- Writing only to and for oneself
- Permitting oneself to write freely and badly
- Writing should not attend to grammar, organisation, logic, evidence or audience
- Writing should appear as if talking

(Charmaz 2006)

Free-writing aided analysis through the promotion of free thinking and I found that it elicited fresh ideas. Further, free-writing helped, in part, to free my thinking from prior knowledge and experiences and in this sense was a valuable tool in terms of critique and reflexivity.

3.9.2 Computer aided qualitative analysis software

Computer aided qualitative analysis software (CAQDAS) is a source of some contention within qualitative research literature, and the use of computer software in qualitative analysis is associated with both positive and limiting factors. This study employed QSR NVivo 9 in storing all data, coding, and other administrative functions.

In terms of the benefits of employing CAQDAS, Green and Thorogood (2014) suggest that CAQDAS facilitates transparency in research through the production of clearer records of coding and theory construction. Further, there are also clear advantages in being able to systematise data storage and in the ability to search and recall data.

However, as noted by Gibbs (2007), the facility of code and attribute searching is only ever as good as the researcher's coding and attribution of the data (Gibbs, 2007: 140). In this regard, it is important to recognise that there is no software able to 'do' qualitative analysis; the quality of qualitative analysis is as contingent upon the sociological imagination of the researcher as it ever has been. Accordingly, the strengths and limitations of CAQDAS are surmised well by Bazeley and Richards –developers of NVivo – who suggest that the metaphor of *craft* remains relevant: 'the excitement of this sort of research (CAQDAS) is that no matter how good the tools, the outcome depends on the researcher's crafting of theory' (Bazeley and Richards, 2000: 91). Throughout this study, CAQDAS has been invaluable in the storage and administration of data; however, CAQDAS has only ever been a tool, and has not assisted the creative process of analysis.

3.10 Objectivity, reliability and validity in qualitative research

Objectivity, reliability and validity articulate key epistemic principles within much health sciences research. Further, the degree to which objectivity, reliability and validity are achieved is often used as a yardstick for measuring quality in research. In qualitative research, however, the relevance of these terms is contested. The following section will address objectivity, reliability and validity, and how they have been conceptualised within this study.

A common criticism levelled at qualitative research is that the knowledge produced through interviews may not be regarded as objective. However, such an argument fails to take account of the fact that the concept of objectivity is itself, rather more ambiguous than is generally assumed. For instance, MacIntyre (1988) has argued that 'Objectivity is a moral concept before it is a methodological concept, and the activities of natural science turn out to be a species of moral activity' (MacIntyre, 1988: 37). In this sense, the quest for objectivity within qualitative research is to be regarded as much an ethical exercise as it is a methodological one. However, the question as to whether or not such objective 'value-

free' knowledge is possible is questionable. Following the influence of hermeneutics, and particularly that of Gadamer (1975), it is difficult to argue against the assertion that the production of knowledge is shaped by the prejudices inherent in all of us. In recognition of this, an important sentiment within qualitative research is that of reflexivity. A reflexive approach may be summarised as one which seeks to identify such prejudices, reflect upon them critically, and makes this process available to the reader. Accordingly, Kvale and Brinkmen (2009) suggest that 'Striving for sensitivity about one's own prejudices, one's subjectivity, involves a reflective objectivity' (Kvale and Brinkmann, 2009: 242). Such a 'reflexive objectivity' may be regarded as a conceptualisation of objectivity more relevant to interpretive approaches, and one with the potential to improve quality in qualitative research. The notion of reflexive objectivity was an important ethical and methodological intention within this study. It is for this reason that I have chosen to include Chapter Six ('Theoretical review'); this chapter details a critique of social capital theory which emerged throughout the process of data analysis, a process which required me to recognise my own theoretical assumptions before seeking to move beyond them.

Reliability is a further problematic term for qualitative researchers, particularly as reliability confers strong moral connotations in everyday language use. Reliability is usually invoked in the evaluation of the trustworthiness and consistency of study findings. There are several ways by which attending to reliability may strengthen a qualitative research: consistency in the transcription process, for example. However, if too great an emphasis is placed upon the reliability, there is a risk that richness in qualitative data will be compromised. In this study, aspects of sampling, recruitment, and data management were conducted in a highly consistent manner; in this sense, contributing towards the 'reliability' of study findings. However, to allow for creativity, innovation and variability, interviews were purposefully flexible and diverse in their structure and content.

Validity in health research is usually associated with the concept of external validity, or the extent to which study results may be generalised to wider populations. As such, a

common criticism of qualitative research is that knowledge created through interviews may not be treated as valid because it is not possible to generalise beyond the subject. Kvale and Brinkmann (2009) provide a useful typology of the structures of such validity claims, these include: the correspondence criteria, the coherence criteria, and the pragmatic criteria of truth. Without reiterating what has already been stated regarding epistemology, the correspondence criteria (whereby knowledge corresponds to an objective or material world) is problematic for an interpretive approach. By contrast, the coherence criterion considers truth claims with respect to the degree of internal consistence and logic within that truth claim, while the pragmatist tradition privileges the degree by which truth claims serve a real-world purpose and enable useful application (Rorty, 1978). Qualitative research more often engages – to varying degrees – with coherence and pragmatist truth criteria. Whittemore, Chase and Mandle (2001) provide a useful practical model along such lines, and distinguish between primary validity criteria – those necessary to all qualitative inquiry, but which are not sufficient in themselves – and secondary validity criteria – considered more flexible in their application. Primary criteria for qualitative validity are identified as authenticity, criticality and integrity. Secondary criteria are identified as explicitness, vividness, creativity, thoroughness, congruence, and sensitivity (Whittemore, Chase and Mandle, 2001: 529). This model is similar to that of Kvale and Brinkmann (2009), who advocate the model of the researcher as ‘craftsman’: attentive to questions of validity not simply as an external evaluative measure, but as a guiding principle throughout the whole research process. Considerations of qualitative validity, particularly by reference to the aforementioned qualitative-specific models, have been important to the conduct of this study; such measures of qualitative ‘validity’ contribute towards the integrity and coherence of this thesis.

3.11 Reflexivity

As a researcher, reflexivity involves reflecting upon one’s personal values and actions and assessing to what extent, and in what ways, these factors impinge upon and transform all

facets of the research process. Failing to recognise the role of one's personal, social and cultural positioning risks the production of knowledge which simply reflects the situated purview of the researcher. Reflexivity in this study was an ongoing process rather than a post-hoc appraisal, and key reflexive moments occurred throughout data collection, during the analysis of data and theory construction. The following section details key moments of reflexivity and explains the consequences of reflexivity for this thesis.

The most immediate instances of reflexivity occurred during data collection and relate to the interviewer-interviewee dynamic. In-depth interviews are not socio-culturally neutral events, and are likely to be the site where intra- and interpersonal socio-cultural factors play out. Therefore, as an interviewer, my appearance, manner and gestures will, to some extent, have shaped the data produced. From the perspective of participants, I will have appeared as an ostensibly healthy, relatively young, white man. As is described in Appendix 1, participants in this study were all older people living with multiple chronic conditions. The disparity between me and participants in terms of age, health and (in the case of female participants) sex will have been obvious and may have acted as barriers to trust and rapport. Indeed, I felt that two participants may have withheld certain details about their health. One female participant was reluctant to talk about certain aspects of her health – she used the term 'waterworks' in reference to her urinary problems and was visibly uncomfortable when talking around this issue. Her use of euphemistic language suggests she was embarrassed, and it is certainly possible that this embarrassment will have been exacerbated by her interviewer being a younger male. Another participant, this time male, appeared reluctant to talk openly when it came to the emotional impact of illness. This participant presented himself as a strong (both physically and mentally) and self-sufficient man. I sensed he was reluctant to confront emotionality because to do so would undermine the masculine ideals vital to his identity. Again, it is possible that my sex, age, and health status influenced this situation. If this participant did feel that his identity, grounded in masculinity, was at risk, then these feelings may have been

pronounced by our contrasting age and health, and furthered by the fact we are both men. It is realistic to assume that an interviewer of similar age, health profile, sex (in the case of the female participant), and who shared common biographical traits with participants, would not have experienced these barriers to open communication, and may have produced different data. However, employing an alternative researcher was not possible, so I took steps to build relationships with participants which were professional, yet personable, and which encouraged rapport and trust. To this end, I spoke with participants at length about the research, non-research topics, and myself – my professional experience, my doctoral studies, and my personal life (where this was appropriate and conducive to a more productive researcher/participant relationship). In general, I felt these strategies were successful, and the vast majority of participants appeared to be comfortable talking about what were, at times, difficult and intimate experiences of illness and social support. Despite this, such open and trusting relationships were not possible with all participants, and it is likely that a small number (as identified above) remained wary and guarded when talking about the most intimate aspects of their personal and social worlds.

A small number of participants appeared to regard me as a person of high social status – two participants were under the impression that I had a background in clinical medicine, whilst others indicated that they considered medical research to be an esteemed activity. As a consequence of this, I felt that some participants used their interviews to present themselves as morally virtuous – as ‘good patients’, for example – perhaps in order that I, as a person of perceived high social status, should recognise them as such. This morally performative dynamic does not invalidate the accounts given by participants as the interpretive approach does not rest upon, nor assume, the objectivity of participant data. However, it was important that my presence, and my apparent social status, did not determine the course or content of interviews, nor elicit accounts which were intended solely to achieve my recognition. Accordingly, I made efforts to counter participants’

assumptions about my social and professional status and sought to establish myself as, at most, an equal partner in the research relationship. I explained to participants that I was a social researcher rather than a clinical researcher, I corrected participants whenever they referred to my supposed medical background, and I made various other self-deprecating statements and gestures to encourage parity of status. Overall, I considered these strategies successful as they resulted in interviewer-interviewee dynamics which were more equitable. Most participants were apparently unconcerned about my moral judgement or recognition. However, among those who were, this concern appeared to wane throughout the first interview and by the second interviews (which were, universally, more relaxed and open) participants no longer appeared to present themselves as virtuous in any contrived sense, though they continued to speak about illness and support in ways which highlighted the importance of morality in their personal and social worlds. To this end, all participants spoke about having fallen short of various moral virtues, a fact which suggests that my status, and the interviewer-interviewee dynamic, did not prevent participants from speaking openly, nor elicit moral narratives which were overly performative.

Reflexivity was also important during data analysis and theory construction. As a principle of reflexive practice, I was forced to reflect critically upon the theoretical assumptions I brought to the research process and the role that these assumptions played in data analysis. This process of critical reflection significantly altered the course of this study, the theory upon which this thesis called, and the analysis and theory contributed by this thesis. These issues are explored in greater detail in Chapter Six (Theoretical Review), but the role of reflexivity in this process is worthy of brief exploration. During the initial stages of data collection and analysis, my approach to research was influenced heavily by social theory derived from social network analysis and theories of social capital. At this early stage, I was guilty, at times, of applying theoretical concepts without adequate critique, and allowing theory to lead analysis, rather than building theory which was

grounded in the data (a key principle of grounded theory). Upon reflection, it is likely that this naïve approach to data analysis resulted from my lack of research experience (I was a junior researcher with post-graduate training in social research methods and approximately 18 months experience as a professional qualitative researcher). Fortunately, the principles of reflexivity (and the procedures of data analysis cross-validation carried out by the research supervision team) encouraged me to question my theoretical presumptions throughout data collection and analysis. This led to the realisation that social network analysis and social capital theory were useful only at a superficial level, and were not sufficiently sophisticated nor sensitive enough to explain the complexity apparent in participants' experiences of illness and support. As a result of this realisation, I engaged in the wider theoretical literature and drew upon different theoretical concepts which illuminated and brought clarity to complex data. In this sense, reflexive practice was key to my development as a researcher, as well as the theoretical contribution made by this thesis.

3.12 Ethical issues

Ethical approval for the study was achieved from NRES North-West Cheshire Ethics Committee (11/NW/0825). Following an initial ethical review, a number of requests for further information were made by the committee; these issues related to minor amendments in the study information literature and consent forms (see appendix 16).

A further ethical amendment was submitted to, and approved by the (above) ethics committee during data collection. This amendment related to the timing between participants' first and second interviews. Initial ethical approval had committed researcher and participants to a fixed six month time gap between interviews; however, this inflexibility was not practically helpful. The ethical amendment enabled the second interview to take place between three and six months after the first interview (see appendix 18). This amendment was approved by 'Chair's action'.

All participants received a study pack (study information literature, consent form, pre-paid return envelope) by post. Upon receiving returned completed consent forms, I made telephone contact with participants and undertook efforts to explain the research further and encouraged participants to ask questions about the research and the study process (my intention being to ensure participants were in possession of the information they felt necessary in order to consent). Furthermore, at each interview I made similar efforts to explain the research, and to provide opportunities for participants to ask any questions; I also read through the consent literature at the beginning of each interview, and confirmed participants' desire to consent.

Beyond formal ethical process, ethical issues were confronted on a regular basis throughout data collection. My own conduct in such instances may be seen as informed by a principalist approach towards research ethics. In this respect, ethical conduct was informed by a respect for autonomy; beneficence; non-maleficence; and justice (Wiles, 2012). The most common invocation of such ethical principles occurred as participants became upset or distressed during interviews. The issue was not uncommon and occurred most often during discussions about the impact of illness upon personal relationships and in relation to the topics of interpersonal dependency. In these cases, I was very concerned to minimise any distress participants might experience and I often ended a line of discussion where I felt participants were confronting issues which were too difficult. Undoubtedly, in these instances, it is possible that potentially rich data was forfeited, however participants' wellbeing took precedence over any such concerns.

3.13 Data management and security

All interview transcripts and interview audio files were stored on password protected secured servers. No data was transferred to personal computers. Field notes and hand written memos were stored in locked filing cabinets.

3.14 Conclusion

This chapter has outlined issues of methodology, study design and methods within this study. Central to these issues has been an explication of my epistemological and ontological perspective, and an open and frank description of the processes of data collection and analysis. This chapter may be read as an important stage of theoretical and methodological reflexivity; in detailing philosophical and methodological issues, I hope the reader will be better able to 'interpret my interpretation' of the data which follows (Alvesson and Skoldberg, 2000). This thesis will now begin the process of presenting participant data and answering the research questions set out by this thesis.

Chapter Four: The lay meaning of multimorbidity

4.1 Introduction

This chapter explores how people with living multimorbidity experience concurrent conditions as meaningful. The first part of this chapter will address the biomedical assumption that multimorbidity is defined by the presence of concurrent diseases. It will be argued that labels of disease status and concurrency often do not resonate with lay experience. It will then be argued that people living with multimorbidity make sense of illness according to distinct logics of meaning. Examples of such logic will be defined, with the influence of corporal and socio-cultural factors identified. In conclusion, it will be argued that the lay meaning of multimorbidity is often at odds with the biomedical concept of multimorbidity: understanding lay meaning requires an appreciation of the intersecting corporal, biographical, and socio-cultural logics within individual cases. These conclusions will be discussed in terms of their consequences for current perspectives on multimorbidity self-management, particularly the notion of illness prioritisation.

4.2 What it means to live with multimorbidity

According to the biomedical perspective, an individual with multimorbidity lives with more than one chronic condition or disease, and these conditions or diseases are present in a concurrent fashion. These assumptions are largely accepted within related literature, and yet, in discussing multimorbidity with participants in this study, these assumptions become problematic. The following two sections outline the ways in which participants questioned the nature of illness-status and concurrency.

4.2.1 Multiple chronic illnesses but not ‘ill’

For some participants, the notion that they lived with multiple chronic conditions was questionable. David, for example, did not recognise himself as living with multiple conditions. As David spoke about his health, he detailed the ways in which illness affected everyday life; David’s mobility is limited and he experiences difficulties in completing tasks

such as domestic work without assistance. Further, David has also made significant changes to his diet following grave advice concerning diabetes management. In recognition of these issues, I was keen to understand whether or not David considered a particular condition or symptom to be a priority. However, in replying to this line of questioning, it soon became clear that David did not understand his health in these terms:

I've got the diabetes, I've got the blood pressure, I've got arthritis in me knees, fair enough, but to me, I'm not ill. It's just an inconvenience. It's like if you break your arm, you, you've got one arm in a bloody sling, you've only got one arm to work with. You're not ill, are you? If you know what I mean.

David, 1st interview

Despite living with a number of clinically diagnosed chronic conditions, David rejects the assertion that he is living with illness. Rather than considering his health in terms of clinically diagnosed conditions, David frames illness in terms of how it affects his life – David's conditions are an 'inconvenience' rather than an illness *per se*. I sought to gain further insight into what illness meant to David, and how this knowledge related to his own health:

Int: So perhaps *give me an example of what, of when you would be ill...*

David: *If I was ill I'd be, I'd be in pain... stomach, chest, you know, the bits that matter in the middle [points to abdomen]. That, that's being ill to me...*

Int: *Something inside you, kind of, that you can't...*

David: *Yeah. You've got no control over it. And as I say, my cousin's wife, she was as right as nine pence one minute, and the next minute she's bloody collapsed, and they fetched the paramedics out to her, she was in XX [Local hospital], and, removed her gallstones. That's something you've got no*

control over. You know, appendicitis, or if you've got bloody transplants, that's being ill.

Int: *And not the kind of stuff that you just live with?*

David: *No no. As I say, if you break your arm, you're not, you're not ill. It's a bloody inconvenience. Well, it's like my knees. They're an inconvenience, but it's something you've got to put up with.*

David, 1st interview

In the above exchange, David reflects upon the concept of illness and identifies what he considers to be its defining features. For David, illness is something associated with internal – particularly abdominal – organs (suggested by David's gesturing towards his abdomen). Illness is also something David associates with a lack of warning, acute onset, or an event which is difficult or impossible to control. David identifies gallstones and appendicitis as examples of illness – these conditions characterised by acute abdominal pain. As a further example, David identifies 'transplants' as indicative or constitutive of illness – we might interpret this in terms of illness requiring complex and invasive clinical intervention.

David, therefore, has a firm understanding of what it means to be an 'ill person', and he considers his own ill-health in relation to this. David does not experience any of the issues he associates with illness: he does not experience uncontrolled symptoms, he has not required invasive surgery, nor has he been troubled by 'the bits that matter in the middle'. As a result, David does not consider himself to be living with illness; instead, David defines his ill-health as 'something you've got to put up with'. David's understanding of the meaning of illness is clearly at odds with a biomedical model of multimorbidity. Specifically, David does not understand his health as delimited into discrete clinically diagnosed conditions. Rather, David makes sense of his illness in terms of the impact it

has upon daily life – how physical limitations restrict his ability to complete previously valued activities.

Similar issues were raised elsewhere by Mo, a woman living with systematic lupus, OA, depression, and an addiction to Tramadol (Mo identified this addiction as relevant to her ill health). Mo was a nurse by profession and, informed by her experiences both as a patient and as a practicing HCP, brought a particular perspective to discussions. Mo, perhaps more than any other participant, understood the biomedical principles of multimorbidity and recognised the importance of multimorbidity to clinical practice. However, despite this, Mo questioned the relevance of multimorbidity to her own experience of illness:

I don't look at myself as this sort of ill person with all these things going on. I think, even on the worst day, it was always because it was one particular thing that was the problem at the time. So anything else associated or not associated with that didn't really come into... It's like, if it was arthritis that was the problem then that was the problem.

Mo, 1st interview

In this quotation, Mo conveys two particularly strong messages. Firstly, Mo (much like David) questions the label of an 'ill person', and she does not recognise herself as having multiple conditions – 'all these things going on'. Secondly, Mo questions the assumption that she experiences conditions in a concurrent way – 'even on the worst day, it was one particular thing that was the problem at the time'. In reflecting upon this point, concurrency is often tacitly defined and operationalised (as was the case in this study) simply as the presence of multiple clinical diagnoses on an individual's historic medical record. However, Mo emphasises that concurrence is not experienced in such an additive or cross-sectional way, nor in a manner whereby multiple symptoms or conditions are experienced as immediate. Rather, Mo's experience of concurrency is as single conditions or symptoms being perceptible at a single point in time. Mo's example illustrates that

concurrency is itself a problematic motif which is founded upon the biomedical assumption of disease rather than illness. In this regard, it should not be assumed that multiple conditions or diseases are experienced as immediately concurrent; understanding how and why illness, rather than wellness, comes to be foregrounded in individual experience should be a priority.

4.2.2 Illness without diagnosis or explanation

For several participants, the meaning of illness owed less to clinically diagnosed conditions, and was defined in larger part by illnesses and illness-episodes which were uncertain or ambiguous. A common example of such ambiguity came in relation to illnesses described as 'borderline'. Mary, for example, spoke in these terms when describing a recent illness experience:

I had a diabetic foot in October and nearly lost my toe; it went black. I don't have – I'm borderline diabetes; I'm not classed as a diabetic.

Mary, 2nd Interview

In this example, Mary recounts an acute episode of illness – the near loss of her toe – and she identifies this experience as the result of diabetes. However, as Mary clearly states, she does not consider herself to be 'classed as a diabetic'; rather, diabetes assumed the more ambiguous status of 'borderline'. Similar sentiment was present in David's claim that: 'I've diagnosed borderline diabetic, as well now'.

Elsewhere, participants also identified themselves as 'borderline' in relation to hypertension. Pamela, for example, recalled a recent conversation with her GP:

My blood pressure had fallen again but only, probably just in the, sort of, zone he wanted, which was – oh, was it 70 over – no 100 – oh, I can't remember. Something over 70... he said, "Well, it's just still borderline".

Pamela, 2nd Interview

In this example hypertension, as with diabetes, is classed as 'borderline'. The status of an illness as 'borderline' confers a sense of illness being simultaneously present and absent. Illness is present in the sense the individual has an awareness of risk, and there may also be a requisite action – changing of diet or taking more exercise – recommended by a HCP. However, the ambiguity around the status of 'borderline' also defines the illness as absent – as Mary states, 'I'm not classed as a diabetic'. The above examples highlight that the experience of multimorbidity may be shaped by conditions which are not yet manifest. In this regard, conceiving of the lay meaning of multimorbidity must recognise conditions or symptoms which are without a clinical diagnosis.

In addition to illnesses described as 'borderline', several participants spoke about their health in ways which highlighted a general dissonance between lay perspective and a biomedical perspective. During her second interview, Isla spoke about her recent ill health and described one feature of illness which she considered particularly important:

Int: *Has there been anything else at all, health wise, that...?*

Isla: *Well, of course I have, I have a chest problem, but– which just flares up now and again sometimes, but I mean I've had that for goodness knows – a lot of years. So it's not... it's not a chronic, but it's just that – sometimes I wheeze quite, quite a lot and other times it's okay.*

Int: *You've had that for some years?*

Isla: *Just a weakness, yes, yes. I had bronchitis – I caught bronchitis – well, I've lived – I've been here 13 years and it was when I was in XX [previous address], so it's a long time ago. I had to go to the chest – they sent me to the chest clinic. I must've had a very bad cold and infection and I attended the chest clinic for quite a long time. The only diagnosis they could come up with was bronchitis. It wasn't a sort of permanent thing, it was just something – I*

mean even in this warm weather, well it isn't warm at the moment, but in summertime I still have— you know, people would say to me, 'Have you got a bad cold?' I haven't, it's just the rustiness in my throat.

Isla, 1st Interview

Throughout her interviews, Isla detailed her experience of regular episodic chest infections for which she consults her GP and takes antibiotics. Isla's understanding of this illness-issue is marked by a degree of uncertainty; Isla referred to this issue elsewhere as her 'weakness' or her 'chest problem' rather than any particular condition. In the above quotation, Isla identifies a similar episode as having been diagnosed as bronchitis; however, Isla does not consider this to be a chronic illness. Despite this ambiguity, or perhaps because of it, Isla designated this 'weakness' as among her more salient illness concerns. This example further emphasises that to focus upon clinically diagnosed conditions alone – or conditions which are chronic in nature – is somewhat reductive.

For other participants, the relationship between clinical diagnoses and illness experience was yet more incongruous. Bill, for example, was particularly keen to discuss a recent illness-event which he considered especially disturbing (Bill's wife Cath also contributes):

Cath: *Well, we don't know what that was. It was just something...*

Bill: *I felt, one evening...*

Cath: *That settled on his stomach and he was really bad, and we rushed him into hospital.*

Bill: *It was a Saturday evening, it was, and I says to Cath, I said...'I feel a bit rough,' like, so... Anyway, I went upstairs and lay on the bed a bit, and then I had to go in the bathroom, and I was really sick...*

Cath: *Really sick... I thought he'd got a burst ulcer.*

Bill: *I come down here and I was sick again, and rang the out, out-of-hours doings and, it was, well, it was coffee granules, they...*

Cath: *That's what they call it.*

Bill: *Still don't know, that's what they called it, even in, in the hospital in XX (local hospital), they called it coffee granules and, we still...I mean, if we ring, same as travel insurance, they want to know all these things, I suppose, and there's nothing in the manuals, apparently, to describe what it is.*

Bill and Cath, 1st Interview

In the above example, Bill and Cath discuss an acute episode of illness. The unexplained or ambiguous nature of this illness has had a lasting effect, and this episode continues to puzzle and worry Bill. For Bill, the remarkable feature of this event is that 'there's nothing in the manuals, apparently, to describe what it is'. In the absence of any clear clinical explanation, Bill and Cath are left with a vernacular explanation – 'coffee granules'. The term 'coffee granules' is widely employed in reference to gastro-intestinal bleeding, and could reasonably be associated with – as Cath suggests – Bill's history of stomach ulcers. However, Bill and Cath do not possess this knowledge, and this illness-episode has come to be defined through its ambiguity. This example is a further instance of the illness experience being shaped by an acute episode of illness; here again, it would seem insufficient to focus upon clinically diagnosed or chronic conditions alone.

The above examples invite us to question the assumptions which underpin biomedical definitions of multimorbidity. Individuals living with multimorbidity may understand the meaning of conditions in a manner which is at odds with bio-medical standards. Where illness does not align neatly with clinical diagnoses – such as 'borderline' conditions, or conditions lacking a clinical diagnosis – the ambiguity surrounding the condition may become meaningful in itself. Further, the notion of concurrency may have little relevance to individual experience – having a medical record of concurrent illnesses does not mean

that illnesses are experienced in an immediately concurrent fashion. Finally, a singular focus upon chronic conditions seems problematic. In particular, the lay meaning of illness often does not conform to an additive model of chronic diseases (as is assumed by the biomedical definition of multimorbidity), and acute illness must also be recognised as contributing the meaning and experience of illness.

4.3 Lay logics of meaning

While the lay meaning of multimorbidity appears at odds with a biomedical perspective, it would be remiss to assume that it is irrational. Rather, interviewing participants about the meaning of multimorbidity highlighted rational and distinct lines of reasoning which allowed sense to be made of illness. The following sections detail a number of these distinct lines of reasoning as they appeared in participants' accounts of multimorbidity.

4.3.1 Normality and control

Chronic illness has been described as an experience wherein previously taken-for-granted structures of everyday life, and the forms of knowledge which underpin these structures, are disrupted (Bury, 1982). For many participants in this study, the meaning of multimorbidity was defined by the degree to which illness and symptoms affected (or threatened to affect) these previously stable structures of life.

Several participants spoke about their desire to 'carry on as normal' despite living with multiple conditions. In these cases, illness and disability were discussed in terms of how symptoms and physical limitations threatened images of normality. Where illness could not be accommodated into what participants considered normal, illness was propelled into

the foreground of experience.¹¹ Bill spoke about the meaning of multimorbidity in these terms:

I mean, it's there, you know, these things... one, two or three, whatever you've got, arthritis, asthma, you know, you've just got to live with it, you know. It's, it's there, and until, same as I start coughing and doing, in between that, like, you just carry on as normal, you know, and just carrying on until you come to... you try to do something, getting out of a... stuff out of a cupboard or something, then you realise that you've got that condition.

Bill, 1st Interview

In Bill's account of multimorbidity, normality is central in shaping meaning. Bill states that despite living with multiple conditions, he continues to live with illness in the background of everyday experience and he is able to 'carry on as normal'. However, where illness and disability complicate or prevent the accomplishment of previously 'normal' daily activity ('getting stuff out of a cupboard'), illness is foregrounded in experience and the possibility of normality is threatened. Elsewhere Bill recounted further examples of illness impacting his ability to carry on as normal:

You know, I can, I'm living with these aches and pains, as it were, you know? But, quite often now, while this weather's been on, particularly... I've started coughing when I'm in bed, and I've had to get up. I may have gone to bed about 10, 12 o'clock I've had to get up because I'm coughing that much.

Bill, 1st Interview

Bill added:

¹¹ The image of illness in the foreground and background is borrowed from Paterson (2001) and the 'shifting perspectives' model of chronic illness. The utility of this model is discussed further within the Discussion chapter of this thesis.

The night's worse with this with asthma, it's so long, you know, if you are coughing during the night.... It's a long time till breakfast.

Bill, 1st Interview

In this passage, Bill considers the impact of OA in relation to asthma. With regards to OA, Bill states 'I'm living with these aches and pains'. There is a sense by which Bill is able to incorporate the symptoms and limitations conferred by OA into his everyday practices: a 'normal life' is possible (similar findings have been reported by Sanders, Donovan, and Dieppe, 2002). By contrast, Bill identifies asthma as the cause of long sleepless nights during which he experiences bouts of painful coughing. Bill experiences these episodes as highly disruptive, and his statement that 'It's a long time till breakfast' conveys the isolation and suffering which characterise these experiences. For Bill, asthma is simply too disruptive to the practices of everyday life, and for this reason, asthma takes becomes Bill's most salient obstacle to a normal life.

The importance of maintaining normality and the previously assumed structures of everyday life was also apparent in David's case. When asked whether he considered particular conditions to be 'more important', David replied:

David: *Yeah, my knees. I mean I get up in the morning, it takes me quarter of an hour to get in the bathroom until I've got them going again. Don't have a bath. We have a walk-in shower because I can't - I couldn't get in the bath.*

Int: *So that's most important, then, because ...*

David: *Well, if your legs don't walk, you don't go nowhere do you? You know, you're knackered like.*

David, 1st Interview

In the above example, David identifies the ability to walk as a fundamental necessity – 'if your legs don't walk, you don't go nowhere do you?'. At the time of his first interview,

David's mobility was increasingly limited by OA in his knees; however, David was determined to maintain his ability to walk. Elsewhere in his interviews, David railed against the prospect of using a mobility scooter, and was equally appalled at the prospect of 'sitting in me chair all day'. David identifies his knees as his 'most important' health issue because OA, pain, and disability threaten his ability to walk, and as such, most immediately threaten the prospect of normality.

For many participants, a corollary of normality was control. Control may be understood as a synonym of normality, but participants also spoke of control in terms of the motivation for self-management, and in prospective terms, as shaping the meaning of illnesses in the future. In one example, David spoke about the meaning of diabetes in terms which highlight the importance of control. Immediately prior to his first interview, David received a diagnosis of type 2 diabetes. However, by the time of his follow-up interview (4 months later) David spoke about this diagnosis as being relatively insignificant. I asked David why this was the case:

Because I'm keeping it under control. I think I am, anyway. I've got to go back August, for another blood test, and, check-up. But if it stays as it is, or comes down, down again, I shall be quite happy with that.

David, 2nd Interview

Following the diagnosis of diabetes, David (with the aid of his daughter) made significant changes to his diet. David credits these changes, in addition to effective medication, with reducing the risk posed by diabetes. In the above quotation, David makes clear the link between his ability to exert control over diabetes with diabetes being less prominent or significant.

Several participants identified medication as the primary means of regaining and maintaining control over illness and the body. One participant, Ian (who lives with OA,

hypertension, and glaucoma) illustrated the relationship between medication, control and normality:

As long as the medication is controlling the, the blood pressure, I should be fine. As long as I take the eye, the eye drops, I'm, I can't focus with one eye, I have a problem with one eye, and that's been the situation since I was a child really. So I've, I've basically only got one good eye. If I was to lose that, then I would have serious issues, but I'm told that as long as I continue taking the drops; as long as I attend, the eye clinic, regularly, for them to check the eye pressures, then, you know, hopefully, everything's under, under controlled, things are being monitored.

Ian, 1st Interview

In the above quote, Ian discusses hypertension and glaucoma, both of which he identifies as being under control. With these conditions under control, Ian does not consider them to pose an immediate threat to the normal practices of everyday life. However, Ian points out that he has only one well-functioning eye and as a consequence, Ian regards his eyesight as being particularly vulnerable. This vulnerability means that glaucoma is a concern, and the prospect of blindness is clearly troubling – ‘If I was to lose that, then I would have serious issues’. However, Ian stresses that the efforts made to control and monitor his glaucoma – through medication and the intervention of specialist HCPs – are successful. For Ian, the risk posed by glaucoma is mediated by these efforts, and he is able to continue living what he considers to be a normal life, with glaucoma in the background of experience.

For some participants, however, control over illness was not possible and in these cases illness precluded normality. One participant, James (who is living in remission from colorectal cancer), spoke about the difficulties he experienced following radical prostatectomy:

I'm 18 months on and it's still – I've got a nappy on, you know which, sickens me at times, you know. It does, it really does.

James, 1st Interview

James had expected to recover control over his bowels within six months of his operation; however, this was not the case and James identified incontinence as a difficult experience:

You're going out and you think, "Bloody hell, I'd better go and have a wash and change that," because you, you think you can smell yourself, you know, it's... it's not very nice.

James, 1st Interview

James experiences incontinence as an acute lack of control, both in terms of the physical consequences of incontinence, and also the shame or embarrassment inferred by James feeling 'sick' at the prospect of incontinence pads. This example emphasises clearly the importance of control over the body, and the barriers towards normality posed when control is not possible.

The examples of James, Ian and David highlight that for people living with multimorbidity, the meaning of illness is often shaped according to the degree that normality is possible. Normality may be considered in terms similar to those identified by Bury (1982) as the previously taken-for-granted structures of everyday life and the forms of knowledge which underpin these structures. Where a particular condition or symptom threatens this normality, illness is propelled to the foreground of experience. The above examples also highlight the meaning of control as a means towards regaining normality or incorporating conditions into new formulations of normality (Sanders, Donovan, and Dieppe, 2002; Williams, 1984). Further, while some conditions disrupt normality, others – by virtue of medication, monitoring and management – are experienced as controlled and do not threaten normality in the same way.

4.3.2 Biography and normality

For several participants in this study, illness and disability were not recent developments. For some, illness and disability had been a feature of life since early adulthood, childhood, and even from birth. In these cases, illness and disability were interpreted differently than was the case among participants for whom illness was a more recent development. David, for example, spoke about his attitude towards hypertension, self-management, and hypertensive medication in these terms. At the beginning of his second interview, David stated that hypertension was not a significant condition in terms of his general health:

Int: *What about the blood pressure, why is that less important at the moment?*

David: *I've had it that bloody long I don't bother about it, you know....*

David, 2nd Interview

Later in the same interview, I probed this issue further:

Int: *So you've had the blood pressure for a long time?*

David: *I've had blood pressure for a long time; 10, 15 years I've had that.*

Int: *So it's.. it's not that important for you?*

David: *Well, I, I just don't think about it, you know. Five, five mornings out of seven I'll remember to take the tablets; probably twice a week I forget... You might think, and you get halfway to wherever you're going, you think, 'Shit, I've never had me tablet. Bugger it, they'll do tomorrow,' you know.*

David, 2nd Interview

David reasons that because he has lived with this condition for a prolonged period of time, it has come to be less significant and he does not regard it as important – 'I've had it that bloody long I don't bother about it'. David's example highlights that it is possible for

conditions within multimorbidity to be incorporated into everyday life: the length of time a condition has been present is important in this regard.

The incorporation of illness into reconstructed biographies was not limited to asymptomatic conditions, and also included participants whose disabilities conferred significant physical limitations. Theo, for example, exhibited a similar line of reasoning in relation to his congenital foot deformity (Theo termed this his 'clubbed foot'). Throughout Theo's interviews, it became clear that the congenital nature of this condition meant that it was understood differently from Theo's other conditions:

Theo: *The doctor offered me some painkillers and that and I said, 'No, thank you,' I said. The only... what worries is spasmodic... results. And once the fact that the painkiller goes away, if the pain come back so, so I don't want something that is going - another addictive thing, you know. Every, every time you have a time you take a painkiller. Because with my ankle, I'm not being funny now, I'm not looking for sympathy, but I have pain with it all the time. Not now, but when I start walking, I can only walk so far before it aches. But that, that is nothing to do with my health. That's just the way it was born.*

Int: *Okay. So you don't - that's interesting, though, you don't consider that a health problem?*

Theo: *No, no, because I've had that from birth. If you had this, you, you'd be, 'Oh God, get, get off, get rid of it, get off. Oh God, I'll be glad when it swells' you know, like a broken leg. It's like being broken all the time, so I have to be careful with it. But if I kick anything I'm in agony for three days and so I don't kick anything.*

Int: *So why wouldn't you take - you wouldn't take any pain relief for that?*

Theo: *No, I never have taken pain relief, because it, it just - the pain comes back anyway, so ...*

Theo, 1st Interview

Theo states that were another person to live with his disability, then they would experience it as painful and limiting; Theo, however, distances himself from such a perspective, stating that this was 'just the way it was born'. Theo reasons that because he has lived with this disability since birth, it is not a 'health problem' in the same way as his other conditions. Rather, this disability is normality for Theo – 'nothing to do with my health'. Whilst this disability does limit Theo (in terms of mobility) and is a near-constant source of pain, Theo does not consider it to be an 'abnormality' in pathological terms. In line with this reasoning, Theo does not believe that pain-killers are an appropriate response.

A similar example is apparent in the case of Ian who also spoke about long-term disability in biographical terms:

Ian: *My other main problem would be...as a teenager I suffered from osteomyelitis and, or acute osteomyelitis, which meant that I was operated on my right ankle. They removed diseased bone. I was in plaster for 12 months. And now as I've got older it's turned arthritic. So the ankle, even though I, you know, I play regular golf... so when I exercise it stiffens. If I rest it up, when I wake up of a morning, get out of bed, it's stiff. So, I'm limping around for a good, sort of, couple of hours until things, sort of...*

Int: *Okay. On a day-to-day basis, which is, which or what are you most aware of?*

Ian: *Erm, the blood pressure, obviously, because I'm taking medication on a daily basis.*

Int: *Over and above the issues you've got with your ankle would you say?*

Ian: *Yeah, I mean, you just learn to live with that. I mean, it's painful, it's stiff, it aches, but, you know, you learn to live with it don't you?*

Ian, 1st Interview

As a result of osteomyelitis contracted as a teenager, Ian now lives with functional limitation in his ankle. Ian experiences difficulty in walking, and his ankle is the source of regular pain and stiffness – 'I'm limping around for a good, sort of, couple of hours'. However, as the above quotation details, Ian considers hypertension to be a more immediate and prominent health concern. Ian explains that having to take daily medication causes him to become more aware of hypertension. By contrast, Ian explains that his disabled ankle, while being symptomatically more salient, is less prominent. Ian's statement that 'you learn to live with it' suggests that, over time, he has come to regard the pain and disability associated with his ankle as normal.

The above examples demonstrate that where conditions have been present for a prolonged period of time, these conditions may be accorded less significance to the extent that they may not be considered 'health problems' at all. It has also been demonstrated that this logic has implications in terms of attitudes towards self-management (medication, for example) – where conditions are understood to be normal (in biographical terms), medical intervention may be considered inappropriate. This has implications for the ways in which self-management is understood in multimorbidity; specifically, these findings run contrary to much that is assumed within the academic literature addressing illness prioritisation. The above examples reveal that it is possible for more symptomatic and disabling conditions to be accorded less significance where they have been successfully incorporated into the individual's biography.

4.3.3 Ageing and normality

Several participants made sense of multimorbidity according to what has been termed the 'social clock' of illness (Bury and Holme 1991). Accordingly, participants spoke about multimorbidity and particular conditions by evoking a culturally constituted link between ageing and illness. One example was provided by David, who said of multimorbidity:

I just think that it's... it's part of life's rich tapestry, to be honest with you. That it's inevitable that, with age, you're going to have... you're going have issues.

David, 1st Interview

For David, the prospect of multiple chronic illnesses is an inevitable part of the ageing process. Elsewhere Isla also drew upon expectations of ageing in framing her discussion of mobility and her recent decline in physical functioning:

Int: *You said that you're aware that the walking has decreased a bit. Is that in general or in the last six months?*

Isla: *Oh no, that's general, that's pretty much – I think that the last 12 months perhaps has gone –deteriorated a little more, yes. But all I can say is that it's something I have to accept. Of course, my own body as well, my age of course doesn't help because you're obviously not agile anymore. But I mean, as I say, I'm grateful that I am where I am.*

Isla, 2nd Interview

Isla understands her declining levels of mobility to be a normal part of the ageing process and she considers herself fortunate that, given her age, she is able to walk even short distances. Elsewhere in her interview, Isla spoke about the association between ageing and illness in terms which also indicate a condition-specific logic:

I have osteoarthritis in my back, which I take a – I do take a medication for that once a week but I mean you have it in your fingers and that, but that's a natural thing that comes with your age.

Isla, 2nd Interview

In the context of multimorbidity, it is interesting to note that while some conditions – OA and hypertension, for example – were regularly identified by participants as a normal part of the ageing process, other concurrent conditions were not. Cancer, for example, was not identified as 'natural' or as an inevitable part of growing old. In this regard, wider literature has identified specific illnesses as culturally associated with the ageing process: stroke and musculoskeletal conditions, for example (Pound, Gompertz, and Shah, 1998; Sanders, Donovan, and Dieppe, 2002). In the examples identified above, the logic of ageing was apparent in regard to the general presence of multiple conditions (David), but also in terms of specific conditions within multimorbidity (Isla). This would suggest that the association between ageing and illness works at the levels of the general accumulation of multiple chronic illnesses, and also specific conditions within multimorbidity.

4.3.4 Lay biomedical knowledge

Although this chapter makes the general argument that the lay meaning of multimorbidity differs from a biomedical perspective, it is also true that some participants employed aspects of biomedicine in making sense of multimorbidity.

One participant, James, reflected upon what it meant to live with multiple conditions. In discussing the ways multimorbidity had affected his life, James gave insight into why he considered cancer to be distinct from his other conditions:

Cancer is the... is the one that preys on you, really... because they can, you know, they can sneak back anytime, you know. So as long as I can keep that in, I can manage. Because, the other week when I went to, for my, sort of, annual check-up

with my GP, my blood pressure was 135/74, which, which is pretty good, I think. And he said so as well, so he said everything's all right there, so that's under control.

James, 1st Interview

James explains the meaning of cancer and hypertension, and does so through interpreting risk and prognosis. James understands cancer and hypertension according to a hierarchy of risk; he recognises the association between cancer and mortality and also the potential for reoccurrence. By contrast, hypertension is described by reference to his blood pressure being under control – technical blood pressure readings are given in evidence of this.

For some participants, the meaning of particular conditions within multimorbidity was framed comparatively by an interpretation of risk. In such cases, risk and prognosis played a role in defining the meaning of particular illness relative to others. Isla, for example, reflected upon her experience of living with OA and in doing so, drew upon her understanding of Rheumatoid Arthritis (RA):

Isla: *...it's [OA] just something in the joints and it happens and you just live with it, I suppose.*

Int: *So not a health problem in the same way?*

Isla: *Not really, not really, no. Unless you are suffering from rheumatoid arthritis and then that is an illness.*

Int: *Okay, so is that different to osteoarthritis do you think?*

Isla: *Yes, yes. Well, rheumatoid arthritis of course, you know, you lose the – your joints and everything. It's a terrible affliction. As a matter of fact, I was reading some time ago that there are more deaths through rheumatoid arthritis than even cancer or heart disease.*

Int: *My word, okay.*

Isla: *That is really an illness, yes.*

Isla, 2nd Interview

Elsewhere in her interviews, Isla described living with significant pain and disability as a result of OA. Despite this, as the above quotation makes plain, Isla considers OA to be less significant than other conditions. Isla makes comparisons to RA, and draws upon her misunderstanding of RA being associated with mortality. As a result of this comparison, Isla contends that her own illness is relatively insignificant.

For most participants, hypertension was seen as being relatively unimportant (due to its asymptomatic character and the ability to control hypertension through medication). However, where participants discussed the meaning of hypertension, interpretations of relative risk were evident. A clear illustration of this may be seen in the example of Mo, who stated that hypertension was not something which was 'on her radar' because it was controlled by medication. However, Mo also suggested that were her blood pressure to increase, this would become a concern:

Int: *You just said that if that blood pressure was really high, then that suddenly would come onto your radar...*

Mo: *Yeah, god yeah, I'd be thinking 'strokes, heart attack'.*

Mo, 1st Interview

Mo understands the meaning of hypertension in terms of her increased risk of stroke and heart attacks. A further example was provided by Isla, who spoke in similar terms when asked about the salience of hypertension:

Int: *Is it [hypertension] something that you think about day to day?*

Isla: *My blood pressure?*

Int: *Yeah.*

Isla: *Yes, even – I wouldn't say that I think about it, but if you don't feel well, or sometimes you'll get up and you'll not feel on top hole, kind of thing, you do think about it, because something that you worry about more than anything at this age is strokes. Of course, blood pressure – so you do think about it a bit like that.*

Isla, 2nd Interview

Isla clearly infers the meaning of hypertension in terms of risk and the risk associated with her age. This form of reasoning – the association between hypertension and cardiovascular events – would seem to be a clear example of meaning informed by biomedical knowledge.

The above examples highlight a particular logic of lay meaning, one which begins to incorporate knowledge as framed by a biomedicine. Risk factors, clinical prognostics, and pathophysiological associations were apparent in the ways in which some participants made sense of particular conditions within multimorbidity.

4.3.5 Health care professionals

Interactions with HCPs, and particularly GPs, were identified by several participants as conferring meaning upon illnesses and illness events within the experience of multimorbidity.

Bill, for example, spoke about having consulted his GP in relation to breathlessness. Bill identified breathlessness as a significant and limiting factor in his everyday life. However, in apparent contradiction to this, Bill also claimed not to be worried by his breathlessness:

I get breathless. But, they checked my heart out and they said it's not that. Something here [points towards chest], but it's gone no farther, so I'm not bothering them, I'm still going. They'll send for me if they decide to do anything.

Bill, 1st Interview

As a result of his interactions with HCPs, Bill does not consider his breathlessness to be a sign of anything more malign. There is a sense in which Bill trusts the clinical knowledge and judgement of HCPs – ‘They’ll send for me if they decide to do anything’. As a result, despite the limitations conferred by breathlessness, Bill understands this as something to be incorporated into everyday life rather than the subject of further medical intervention.

For some, however, interactions with HCPs contributed towards the experience of suffering. One example was provided by Elaine who spoke of a recent consultation with her GP. Having lived with unattributed pain for some time, Elaine decided to consult her GP and seek resolution. I asked Elaine whether she was satisfied with this experience:

Well, half and half really, because I probably wanted him to diagnose, was it sciatica, but he didn’t actually say that, but, I mean, perhaps he didn’t know, really, because like I say, when he put me on the couch and he said, ‘Can you move, put this leg up?’ Well, he said, ‘Well, some people can only do it like that,’ well I could put it right up like that. And he said that if I can do that it isn’t sciatica. So, I just thought, ‘Well, what is it then?’ Have I pulled a muscle?’ I don’t know, but as I say, it could be, couldn’t it, but he didn’t, sort of, diagnose anything.

Elaine, 1st Interview

During her interview, I gained a sense that Elaine revered her GP, and the fact that he was not able to explain her pain contributed to, and exacerbated, the sense of uncertainty and ambiguity which characterised her experience. Here again, the episode of illness becomes meaning (albeit in an unpredictable way) through interactions with HCPs.

4.4 Discussion

Multimorbidity is widely understood to mean that more than one chronic condition or disease is present within an individual at the same time. However, this chapter has

problematized these assumptions, and has argued that people living with multimorbidity often do not a) recognise clinically diagnosed conditions as accurately representing their health, and b) do not recognise concurrency in their experience of illness. These points formed the basis of a broader argument against imposing a biomedical model of multimorbidity onto the patient experience.

Throughout data collection and analysis, the most striking feature of participants' stories was the huge diversity of experience, and also the distinct lack of uniformity in the ways that illness was understood to be meaningful. Similar issues have been identified in previous research as a lack of 'pattern' to patient experience of multimorbidity (Bayliss et al., 2003), and also in regards to the 'shifting priorities' held by individuals with multiple conditions (Morris et al., 2011). As has been stated in the literature review, these issues have formed the foundations of various models of illness prioritisation with illness priorities posited as informing self-management practices.

However, it has been a conscious decision not to frame this chapter in terms of the illness priorities of participants. This decision was guided by data, and the fact that it was not possible to concur with the widely-held assumption that patient priorities mirrored their self-management practices. This was apparent initially as participants questioned the relevance of concurrency, and did not speak of the need to prioritise conditions at the expense of others. Further, it was also clear that for many participants, ill health was not something which was understood in terms of delimited conditions. As such, the ways in which participants made sense of illness often confounded the logic of prioritisation. This might be illustrated by concrete examples.

In cases where a particular illnesses or disability had been present for a prolonged period of time, participants spoke about illness and disability as not being foregrounded in everyday experience – although illness was present, it was not considered a priority as such. In these cases, illness and disability was incorporated into new modes of everyday practice (Loomis and Conco, 1991), whereby the biographically disruptive aspects of

illness were incorporated or reconciled into reconstructed biographies and reconfigured modes of normality (Williams, 1984; Sanderson et al., 2011). In such examples, individuals did engage in 'illness work', but it would be too simplistic to link such self-management practices with any prioritised condition.

In other examples, participants spoke of the disabling and disruptive features of illness as being a normal part of the ageing process, and as such, not a priority in the same way as an 'unexpected' illness might be. Similar findings are apparent in previous studies where the painful and disabling consequences of OA have been interpreted by lay individuals as a natural and inevitable part of growing old (Charles and Walters, 1998; Sanders, Donovan, and Dieppe, 2002). Participants in this study voiced similar opinions. In such cases a paradox is apparent: pain and disability cause significant disruption, and yet the root condition is not considered a priority in terms of medical intervention or self-management. Here again, the logic and terminology of prioritisation should be questioned in that it fails to capture the reasoned logic by which people make sense of illness.

The above comments are not critique against the reasonable claim that individual motivation plays a role in shaping self-management practices. Rather, it is the specific language (and underlying logic) of prioritisation which seems inadequate to explain the complex relationship between sense making and self-management.

This chapter has suggested that different lines of lay reasoning contribute to the meaning of multimorbidity, and a number of these logics have been outlined. Across the participants in this study, these lines of reasoning were apparent to varying degrees. For some, the meaning of multimorbidity was understood singularly in corporal terms – such as the need to preserve mobility. For others, various different lines of reasoning ran parallel and combined to inform highly individuated and complex accounts of illness. In general, this diversity was a characteristic feature of participants' accounts, and no two participants spoke about the meaning of multimorbidity in precisely the same way.

Perhaps frustratingly for readers, it was this diversity rather than any empirical commonalities which defined the stories of participants. However, recognising this diversity is important for our understanding of multimorbidity more generally. To understand the experience of multimorbidity is to recognise the potential for diversity, and the task of future research should be to discern how the various corporal, biographical, and socio-cultural logics of meaning intersect to inform individual cases.

Chapter Five: Social resources: three participant cases

‘... sociology does not discover what no one ever knew before, in this differing from natural sciences. Rather, good social science produces a deeper understanding of things that many people are already pretty much aware of’ (Becker, 1982: x)

5.1 Introduction

We all have social networks, and each person reading this thesis has known other people as friends, worked with others as colleagues, and most familiar of all, been part of a family. The above quotation, taken from Becker’s classic study of artistic labour and co-operation – *Art Worlds* – reminds us that the objects of sociological enquiry are very often familiar to us. That the objects of our enquiry are familiar, however, does not mean they are banal. It is the sociologist’s task to produce deeper readings of familiar objects; not to disprove, or necessarily to advance upon previous readings, but to be read alongside other interpretations. Through this we begin to *know* what was previously only familiar.

This chapter begins the process of delivering a sociological account of a most familiar subject – people living with illness and the ways they are supported by others. This chapter presents individual participant cases, and sketches out the social worlds of three individuals living with illness: Isla, Mary and Theo. These three participants are similar in many ways; each live with concurrent chronic illnesses, they are similar in age, and all live within a few miles of one another. However, among these participants there is also great diversity in terms of the quality and quantity of their social relationships, and also with regards to the ways in which social resources are realised within these relationships.

The overall aims of this chapter are twofold:

Firstly, in detailing each participant’s case, a number of themes germane to social networks and social resources will be identified. Of primary concern is to illustrate the

diverse nature of participants' social networks and the various ways that social resources are experienced within these relationships.

Secondly, it will be argued that to make sense of social networks and social resources, complexity and diversity must be embraced rather than being written out of our analysis. It is necessary to consider social resources as they are realised in social practice – how they are given and received in social exchange. In this regard, this chapter also lays conceptual groundwork for the data chapters which follow.

5.2 Case studies

The following case studies focus upon a single participant in turn, and details material circumstances, as well as the experiences of social networks and social resources. Each case is based upon the author's own interpretation of two in-depth interviews (totalling approximately 3 hours per participant). Due to limitations of space, each case is significantly abridged.

5.2.1 Isla

Isla is 70 years old and lives with osteoarthritis, hypertension, a respiratory 'weakness', and chronic pain associated with a longstanding hip ailment. In relation to other people in this study, Isla is among the more physically disabled of participants. At the beginning of her first interview, Isla explained how illness and disability have become an increasingly salient part of her life:

Well the thing that I'm disabled with is that 25 years ago I had a hip replacement.

Now this was extremely successful and I had no problems whatsoever in any line of my life. I did every mortal thing I could think of; dancing, walking, you name it and I had no problems. I didn't even know I'd got a hip in. But the surgeon who put it in, before he retired, had said to me that this hip would last me for as long as the good Lord left me on this earth but I would have problems with my bones. Now I didn't

know at that point what he was meaning really, but what has happened is that because the hip is so strong it has worn away the pelvic bone and automatically moved out of the socket and gone into the pelvic bone. So that's what my main disablement is.

Isla, 1st Interview

As a result of this complication, Isla now lives with chronic and disabling pain. In addition, Isla's mobility is also significantly impaired and she stated elsewhere in her interview, 'I'm more or less housebound now'. Despite her physical disability, Isla works hard to leave the house – to attend Church and occasionally to visit shops – but this is only possible through prior planning and with the aid of a mobility scooter. As a result of her disability, Isla relies increasingly upon the support provided by friends and services (taxis and a cleaner) which she for pays using her disability living allowance (DLA). In recent years, Isla's social world has become increasingly defined by her illness; an intelligent, funny, and gregarious character, she now spends the majority of her days confined to the two ground-floor rooms of her home.

Isla lives alone in a small modern house which is part of a quiet cul-de-sac. During her first interview, I asked Isla how long she had lived in her current home, and she recounted her story thus:

We came to XX [immediate town] in the fifties. Then my first home was in XX Avenue, which is just there. Then I moved just across to the main road on XX [immediate town] Road. Then my husband died there and then I bought a bungalow and then these were built and I rather fancied... I'd no idea, when I moved into the one across the road, that this [disablement] was going to happen. I was 60 when I moved across – in here and the reason I moved in them was the fact that I liked where they were because I was so used to the area. I liked the look of them and everything. At the time, I suppose, my friends used to say, 'well are you ready for

this?’ Because when they were built they were built by XX Housing Association as sheltered accommodation. So as I was only 60 – well I was reasonably fit and everything. I had no thoughts of this going like it did.

Isla, 1st Interview

Isla arrived in the local area as a newlywed setting up home during the 1950s. Isla and her husband shared two homes and raised two children – both boys – one of whom died in the late 1970s. As Isla’s narrative details, she has outlived her husband by some decades. Following the death of her husband Isla lived briefly in a small bungalow, however for the past 15 years she has lived in two other houses within the same cul-de-sac. Despite Isla’s 60 year association with the local area, she has no local family. Isla’s remaining son lives approximately 150 miles away, and is married with two daughters.

Although Isla has no local family, she is far from alone. Isla has a large number of close friends and acquaintances living nearby, and these people are a rich source of support, contributing enormously to her sense of wellbeing. Understanding these relationships is aided by an appreciation of Isla’s biography. In discussing her local relationships, Isla stated:

The people that I’m friendly with here I’ve known for so long, you see. I mean I’ve been associated with them not only with the church but with other organisations that I belong to. So therefore you – I can go back, well goodness knows how many years and so – because they live in the area, of course, as well, you see.

Isla, 1st Interview

This statement indicates two important connections between Isla’s biography and her current social network. Firstly, throughout her time in the local area, Isla has always been involved in civic organisations, and this has influenced the quality and quantity of her relationships. Elsewhere, Isla identified her past involvement in the local church and the Townswoman’s Guild as providing the opportunity to meet new people. Further, these

enduring relationships are built upon the common interests and shared values afforded by joint membership of institutions such as the Church. Secondly, Isla identifies that she has lived in the same locality as her friends for approximately 60 years. This prolonged period of local attachment has played an important role in defining these friendships as durable and fulfilling relationships. These features of Isla's social network are intimately connected to her biography, and particularly, to her personal history of local engagement.

As Isla's illnesses have come to limit what she is able to do independently, her friends and neighbours have become increasingly significant. Isla identified one woman in particular as an important source of support:

Isla: *I have a friend across the way that comes in twice a day. She comes in – she's not as old as me but I've known her for many, many years. She comes in every morning and so she'll come in now at about 4.30pm – 4.45pm and stay for an hour or an hour-and-a-half. She's moved in across the way. She's marvellous and she does an awful lot for me.*

Int: *So when you say that she does an awful lot for you, what kind of things?*

Isla: *All kinds of things really, all kinds of things you want. I mean I can't get to the Post Office to get my money – she does all that. Most of my bills I pay direct debit, I don't want her to have anything to do with anything like that, but there are certain things come that need paying and she does all that. She sees to all my – most of my recycling because that's another problem – getting out to the bin you see. She does all that kind of thing. It's amazing really what she does do. So yes, I'd miss her terribly if she went.*

Isla, 1st Interview

In considering the significance and meaning of this relationship, several aspects should be highlighted.

Firstly, this example highlights that some of the most meaningful and supportive relationships exist outside of the family. Elsewhere in her interviews, Isla described how this relationship began in the 1970s when both women lost their husbands within weeks of one another. In later years, Isla supported her friend through a marital separation. Isla identified these shared life events as important in shaping a friendship which is now among her most significant and supportive relationships. This example illustrates the need to recognise life course factors in shaping supportive relationships. Further, whilst kinship relations are often recognised as important supportive relationships, given that family structures continue to diversify in late modernity, it is important to recognise that family members may not always be the most regular or important providers of social resources.

Secondly, the above example begins to illustrate the complexity of social resources. Isla identifies different types of support, including instrumental support (help with recycling) and assistance in managing her personal finances. It is interesting to note the apparent ambiguity in meaning around these different types of support. In relation to personal finances, Isla states: 'I don't want her to have anything to do with anything like that'. This statement indicates that, for Isla, there is a meaningful difference between personal finances and instrumental support. Recognising this issue, we might begin to question the relevance of classifying social resources according to typologies which privilege instrumental or functional meaning.¹²

Thirdly, Isla intimates that even her most supportive relationships are, in some sense, contingent. In concluding her account, Isla states 'i'd miss her terribly if she went'. This caveat conveys a sense that for all the qualities of this relationship, there is an uncertain or insecure aspect to it. Such kith relationships are clearly important, but should perhaps be recognised as more dynamic, or rather, less stable than kinship relations. The

¹² As was detailed within the literature review, academic studies of social support often apply typologies premised upon the instrumental outcomes of support (e.g. House, 1981).

contingency of friendships was illustrated further as Isla discussed a valued relationship which had, in recent months, broken down:

My friend that I've had for 50 years, funnily enough, we've done everything together since we lost our husbands of course. Holidays and everything – every mortal thing. But she's just acquired herself a partner and so of course – well when I say that, he's been in her life for many years. But it's materialised and so therefore she's in a way got out of my life, which has been a big blow.

Isla, 1st Interview

The loss of social relationships is rarely addressed in social networks literature, yet Isla's example demonstrates clearly that the absence of others is a defining feature of her social network. Further, the loss of social relationships may shape those relationships which remain and endure. For example, Isla spoke about losing her friend and the ways in which this affected her relationship with her son. When asked how often she visits her son, Isla replied:

Well actually, not an awful lot. I don't like – I wouldn't like to live in their pockets or anything. But I must admit, and I think it's since this relationship with my friend has gone, that he has covered it more.

Isla, 1st Interview

Isla's claim that her son has 'covered it more' refers to a recent change in their relational dynamic. With the friendship no longer a part of Isla's life, her son now fulfils many of the qualities realised previously within her friendship. This observation has implications for how we understand social networks; specifically, the loss of others – through bereavement or relationship breakdown – should be recognised as shaping the significance and practice of extant relationships.

The ways in which Isla maintains her relationships are varied. Despite the geographical distance separating Isla and her family, she is able to maintain these relationships through

various forms of digital communication. Isla is in regular phone contact with her son, and she also makes use emerging communication technologies (including Skype). Asked how this form of communication technology affects her relationships, Isla replied:

Well, it brings it nearer home, doesn't it really? I suppose the – the Skype, of course, is useful because you can actually see the person you're talking to. You're picking up the phone and – you know you're talking to them and in your mind you can see them, we know, but it is a little step further, if that's the word.

Isla, Interview 1

For Isla, Skype represents a valuable mode of communication, and she associates seeing her family (on screen) with geographic and relational proximity – 'it brings it nearer home'. Isla explained further how she uses this technology:

When they're at home of course they have their computer on all the time, you know, with doing things. So if I put my Skype – my computer on, you can bet your life that he will Skype me, because he can see I've come online, you see. So I tend to put it on 'thinking' – well, I can see whether he's online and I will occasionally Skype them.

Isla, Interview 1

Isla is positive about communication technology, however there is also a sense that Isla works to maintain a distal quality in these digital relationships. Isla states that 'I tend to put it on 'thinking'; this action indicates to others that Isla does not wish to be contacted, and that she is not seeking to make contact.¹³ This is an example of Isla managing her online relationships – Isla does not wish to be overly connected with her family, nor appear as though she is seeking contact with them. This feature of her online relationships is linked to Isla's wider concern to maintain her independence and the independence of her family (discussed below). This aspect of relationship management highlights the ambivalence

¹³ 'Thinking' mode identifies the user as 'online', and allows the user to observe the status of other users without instigating conversation.

with which communication technology may be experienced. Isla values online communication and recognises the positive effect it has upon her relationships. However, this technology also represents a new territory upon which Isla works to maintain and demonstrate her independence.

Although Isla's local network of friends are her most immediate source of support, she also identified family as important. Isla was keen to demonstrate the supportive nature of her familial relationships, and informed me that her son had recently adapted his home (fitting a stair-lift), allowing her to visit in comfort. However, Isla's enthusiasm for this supportive aspect to familial relationships was often equivocal. For example, in discussing the ways in which her son works to maintain contact, Isla cautioned:

But I think it's good for your family if you can be independent. I mean my son will say to me – I mean I remember when he was very busy, when he was working he used to travel all over the world and that, and I tended to wait until he rang me. I would say to him sometimes, if I hadn't heard from him for a bit, "Oh just a minute, I don't recognise your voice". [Laughs] He would say, "Mother, it works both ways, you've got a phone as well". So, you see, I tended to – if I didn't ring him then I wasn't bothering him.

Isla, 1st Interview

Isla's relationships with her family are characterised by her determination to retain independence, and to maintain the freedom of others. As the above quotation makes clear, Isla considers her independence to be virtuous, while receiving support is understood in a negative light. This dichotomy – between dependence and independence – informed, to a large extent, how Isla made sense of supportive relationships. At one point, when talking about the support she received from her son, Isla began to cry:

Isla: *I like to try and be independent, to live my own life like I always have. But she went [friend] – my husband died and she's [friend] 76 and of course XX*

[deceased son] was here then. And when XX [deceased son] died I didn't want him [living son] to have all the responsibility.

[Long pause]

Int: *So you'd rather work hard yourself and....*

Isla: *Yeah, yeah. He used to get on the phone to me and say, 'Why didn't you tell me? Why didn't you let me know?' Because... but I never did, never did.*

Isla, 1st Interview

The ideal of independence informs Isla's attitude towards support, and means that she will often struggle alone rather making others aware of her situation. Isla's example highlights the fact that the receipt of social resources may be a form of moral practice which is, in turn, intimately tied to individual notions of self.

In summarising Isla's case, it is possible to highlight a number of themes in relation to social networks, social resources and health.

Firstly, the relationship between Isla's social connections and her social resources is best understood in the context of her biography. Understanding Isla's 60-year association with her local area is important to understanding the meaning and function of her current social relationships. Secondly observing that the majority of Isla's supportive relationships are with non-family members, we must recognise that supportive relationships are often diverse and unconventional. Further, the ways in which these relationships are sustained, and support exchanged, may be through digital rather than embodied interaction. Finally, Isla's case has begun to highlight the morality of support and assistance. The meaning of social resources is not captured by reference to their function or utility alone. For Isla, the moral ideals of independence and dependence were a primary source of meaning which shaped the significance of her supportive relationships.

5.2.2 Mary

Mary is 70 years old and lives with hypertension, osteoarthritis, type 2 diabetes, and has a history of mental illness; she lives alone in the house that has been her home for nearly 20 years. Mary's biography is particularly complex, and has been shaped by the intersections of mental illness and social deprivation (poverty and low educational status). At the beginning of her first interview, I asked Mary about her early life and she began to tell her story, alluding to some of the challenges she has faced:

Well, I've been an adopted child. I was adopted at six weeks. I'd had an idyllic – to some people I'd had an idyllic childhood. To me own children, even, I'd had an idyllic childhood. Ever since my adult years, I can't blame me husband, there were other reasons as well, there were other boyfriends as well, but none of it worked out. It had gone completely opposite; from an idyllic childhood, completely opposite once I'd grown up.

Mary, 1st Interview

Mary's early adult years were particularly difficult and she experienced a number of disruptive life events (stemming from her ongoing struggles with mental illness). Mary married at a young age and had two children, a boy and a girl. However, Mary's marriage was a deeply unhappy experience and, following an acrimonious divorce, she was left to raise her children alone. Mary experienced parenthood as particularly difficult, and within a short period of time her ex-husband was awarded custody of both children. At this point in her story, Mary recounted an event which continues to shape her life today. Mary told me how, approximately 20 years ago, she experienced a violent incident involving her daughter and her ex-husband's partner. This episode occurred following Mary's impromptu decision to visit her daughter:

Instead of knocking - he'd got custody, I'd only got access - instead of knocking, I opened the back door. She went ballistic, this girl [ex-husband's partner], and knocked me against the glass panel. Of course, I ran after her, and all I could see,

boxes, boxes everywhere. They were obviously moving to this private house... Of course, I followed her [ex-husband's partner] she ran upstairs to the bedrooms, and I followed her in every one of them slapping her.

Mary, 1st Interview

This incident resulted in Mary being arrested and prosecuted for assault. Mary received a non-custodial criminal conviction. In addition, in lieu of a custodial sentence, Mary was required to attend what she termed 'psychiatric outpatient services'; a service with which she continues to be involved to this day. In the years following Mary's arrest, her children were taken into institutional care and subsequently placed with foster families:

The fostering service split them up and one went in one home and one went in another. They were together initially, and then my boy ended up in the children's home at XX [town 5 miles away].

Mary, 1st Interview

Throughout this period, Mary maintained contact with her children. However, this contact was irregular, and Mary was often required to act surreptitiously in order to contact her children. Mary gave an example of the ways in which she sought to maintain her relationship with her daughter:

She used to be a Saturday girl at XX supermarket, which was in XX (local town), and I used to meet up with her...I would never go there, but my mother used to make arrangements for me to meet her, because she was only eight when she went into care. And the man next door, there was an old man there, used to, she used to ring him, I wasn't on the phone then, and I used to get me bike out. He used to shout me and say, 'Mary, your, your daughter's at your mother's,' and I used to get me bike out of the shed and go and see her.

Mary, 1st Interview

Today, Mary's children are both adults. Mary's daughter lives nearby, while her son lives approximately 200 miles away. Mary is still in contact with her children, however these relationships are marked by the difficulties and disruption which characterised their childhood.

Interviewing Mary about these relationships was difficult. Mary spoke knowledgeably about her children's lives, their families, and their relationship with one another. However, Mary would also contradict herself when discussing the quality of these relationships and the frequency of their contact. For example, Mary initially claimed to visit her son regularly and she recalled past visits to her son's home with meticulous detail. However, throughout her interviews, it transpired that Mary had not seen her son in over a year, and that any form of contact – telephone or otherwise – was a rare occurrence.

In contrast, Mary's relationship with her daughter was based, seemingly, upon more frequent and regular contact. However, Mary described this relationship as difficult – 'I go and see her, but I have to do all the running really, very poor contact'. Mary's relationship with her daughter sounded, at times, as though it was under significant strain. Later in her interviews, I broached this subject, and asked Mary whether she considered her daughter to be a reliable source of support:

If I said... well, she knows, I mean I don't bother her. I don't – say I was to phone her for the weekly shop, for anything like that, she knows I'd phone her, I'm really desperate, I can't manage with...

Mary, 2nd Interview

Mary struggled to define the parameters of this relationship, and to what extent support might be available. However, Mary clearly felt uncomfortable about the prospect of asking for support, and she stated that she would only ask in emergencies, when she is 'really desperate'. This perspective was further emphasised by Mary's statement that:

I don't put her to the test, you see, because every...because she will tell you, 'I can't do it mum. I, I have to work'.

Mary, 2nd Interview

Later in her interviews, I sought to clarify whether this relationship offered support on a more regular or 'day-to-day' basis:

Int: *So you wouldn't ask her [daughter] for the day-to-day stuff?*

Mary: *Oh, no, no... Well, she reckons – and I've no, no reason to doubt her – there's a device on her desk, she works from home, there's a device on her desk and XX [employer] know when she's left her desk. It's not as easy as what you think.*

Int: *No, no. I can imagine...*

Mary: *Because when she said she was working from home I thought, "Ooh, this is all right", you know?*

Int: *So, in terms of, like... the day-to-day stuff, who would you, who would you ask if you needed a hand doing something?*

Mary: *Well, there's nobody really. I'm under the Active for Age team.*

Mary, 2nd Interview

This was a difficult issue for Mary to confront, however she affirms that she is unable to ask her daughter for support or assistance. Instead, Mary cites a third sector organisation – the 'Active for Age team' (which I understand to refer to the 'Active Ageing' programme, a local Age UK exercise and falls prevention service). That Mary should identify this service as her primary source of social support illustrates that her children do not represent supportive relationships in any significant sense.

In terms of her wider social network, Mary spoke about a weekly mental health peer support group. This group was Mary's most stable and regular form of social contact. Mary described this group:

It's supposed to be a drop-in group. It's a mental health support group... you go there to unwind and that's the idea of it. Funds stopped it, you see. The cuts in funds stopped it and we've kept it going on a voluntary basis.

Mary, 1st Interview

Mary talked about her role as an organiser within this group, and it was clear from her enthusiasm that she valued her responsibilities. However, the nature of Mary's relationships with people in this group remained somewhat unclear. Mary spoke about people at this group as friends, and yet, she would also employ language adopted from professionalised social care:

Int: *You spoke about the group last time and you said that there were a couple of pals there, a couple of friends there that you socialised with?*

Mary: *Oh yeah, I socialise with all of them now, yeah. They all come and we've got very– while we're there we support each other, you know, it's very good. One of the clients has just had her hip done, so that was a – I wanted to know how she'd got on.*

Mary, 1st Interview

In this quotation, Mary describes relationships in social terms, and yet she also refers to a fellow group member as a 'client'. The use of such terminology may simply be a reflection of the formal context of these relationships (within the context of a mental health service). However, this language may also be an indication that these relationships are not particularly close or intimate. Mary certainly experiences these relationships as supportive within the context of group meetings, however recalling the fact that Mary has nobody to

provide routine support, we might also assume that these relationships do not extend beyond the bounded setting of those meetings.

In contrast to most other participants, Mary did not regard her locality – her ‘community’ – in positive terms. Rather, Mary spoke about her fear of the area and her distrust of local people. During her first interview, Mary recounted a conversation she had with a healthcare professional (HCP) following an operation. Here, the HCP was attempting to understand Mary’s domestic situation in an effort to support her return home:

Mary: *He said, ‘Haven’t you got any neighbours or anything that could help you?’ I said, ‘Oh, they’re not appropriate’. They’re not XX [researcher]. There are only the ladies that are 88, they’re the only ones that are appropriate, that you would have a daily conversation with. They’re not appropriate.*

Int: *What do you mean by, ‘They’re not appropriate?’*

Mary: *Well, I never knew what cannabis was until they come there.*

Mary, 2nd Interview

Mary suspects that her neighbours are cannabis users and she considers this abhorrent. In recounting her conversation with the HCP, Mary depicts her relationship with her neighbours as fractious. Elsewhere in her interviews, Mary spoke of neighbours being aggressive towards her, and she recalled experiences of vandalism and violence against her property. In general terms, these issues serve as a reminder that the concept of ‘community’ and ‘neighbourhood’ should be understood critically. While there is a good deal of enthusiasm in health and social care policy with regards to the potential for community as a positive factor (DH, 2010), Mary’s case highlights that community may be characterised by mistrust, fear and even violence.

In summarising Mary’s case, there are a number of issues raised with regards to the meaning of social networks and social resources.

Firstly, we see in Mary an individual who is objectively well connected – she has contact with her daughter and with friends from her peer support group. However, Mary also identified herself as lonely and socially isolated. We might assume that Mary's relationships with her children afford her a degree of support and assistance, but this is not the case. These observations emphasise the need to focus upon the qualitative features of supportive relationships, and in particular, their biographical context.

Secondly, Mary's example highlights that the role of locality and 'community' must be understood critically. Mary experiences her locality as a source of stress and anxiety rather than as a source of social resources. We might usefully consider the meaning of 'community' as the abstraction of the individual's local relationships. In Mary's case, the experience of 'community' is one of fear and anxiety.

Thirdly, Mary's story underscores the complexity of social resources, and in particular, the nuances of meaning involved in the exchange of social resources. Taking the example of Mary's peer-support friendships, we know these friendships do not offer support beyond the boundaries of the weekly group meeting. But why is this? There are clearly nuances as to what forms of support are considered available and acceptable, these issues being shaped both by the qualities of individual relationships and by the institutional frameworks within which relationships are realised. These issues will be addressed in further detail throughout chapters Seven and Eight.

5.2.3 Theo

Theo lives with hypertension, osteoarthritis, and a congenital foot deformity (which Theo calls his 'clubbed foot'). In addition to his chronic illnesses, Theo has experienced a number of 'mild' strokes, and in the past 12 months has also suffered heart failure.

At the time of his first interview, Theo was recovering from an operation to fit an artificial pacemaker. During his interviews, Theo stated that in the wake of his heart failure he had confronted the possibility of dying. Fortunately, at the time of his first interview, Theo's

health was improving and by the time of his second interview (4 months later) Theo's health was such that he was almost unrecognisable from our first meeting.

In recent years, as Theo's health has deteriorated, his wife (Anne) has undertaken an increasing amount of labour in caring for Theo and managing their lives. Theo summarised this as Anne having 'taken the reins a bit'. As with the previous cases, it is helpful to consider Theo's social network and social resources in the context of his biography. I interviewed Theo and Anne together, and I asked them to tell me how they had come to live in their current home. Anne began to recount their story:

We bought this house when it was just a concrete slab actually. They hadn't built it – we'd bought the house.

Anne, Theo's 1st Interview

Theo and Anne have lived in the same home for 38 years. During their time together, Theo and Anne have raised two sons who are now both adults. Theo's sons live some distance away (approximately 50 and 200 miles away). Anne reflected upon this feature of their lives:

We haven't got any family in XX (immediate town); absolutely no family whatsoever.

Anne, Theo's 1st Interview

As a younger man, Theo spent much of his working life as a contracted engineer overseas, and this experience continues to shape his and Anne's social network. Throughout his professional life, Theo was not a regular presence at home. Consequently, Anne became increasingly involved in local civic organisations, and this resulted in her forming a large and durable local social network.

We've built up – I have more [friends] than Theo because Theo's worked away and so he hasn't had the grounding. But I've been in XX [immediate town] so – my friends in XX [immediate town] I know them and I do more with them than I do with

my family because they're here. Do you know what I mean? I have got brothers and sisters but they're not here. They're on the phone and I can ring them any time. That phone call just now was from a 92-year-old lady and she was ringing up because she knew Theo had gone to the hospital yesterday and she was ringing up to ask how he was, you see. The little friends I had from the Welsh chapel.

Anne, Theo's 1st Interview

Anne's comments affirm the importance of locality; she stresses her 'grounding' in the local area, and stresses the importance of friendships formed through years of involvement in her local church. I sought to discover more about Theo's attitude towards friendship, Theo contrasted himself to Anne:

Theo: *She's very gregarious I think is the word and so she has quite a lot of friends.*

Int: *Is that different to you?*

Theo: *More or less yeah. I had two friends; one of them's gone, and the other one's across the road there.*

Theo, 1st Interview

Theo states that he has just one local friend, and intimates that he is not as gregarious as his wife. However, despite this fact, it would be a mistake to consider Theo to be socially disconnected or isolated. Rather, to understand Theo's social network requires that we consider Anne's social contacts, and the extent to which Theo is connected to others through Anne. Anne summed up this feature of their situation concisely:

I have a bigger circle of friends in XX [immediate town] than Theo has, but now he's got them as well.

Anne, Theo's 1st Interview

This example highlights the need to consider individual's social connectedness beyond their immediate social contacts. Reminiscent of Granovetter's (1973) argument for the

'strength of weak ties' (wherein social resources may be available to an individual through third parties), Theo is able to call on Anne's friends for support should he need it.

Focusing solely upon an individual's immediate social contacts may be an unhelpfully reductive way to conceptualise the supportive practices of relationships.

In discussing the availability and provision of support, Theo was unequivocal in identifying Anne as the most important person in his life. I asked Theo to expand upon this point:

Int: *So in terms of getting help from other people, is it mostly between the two of you then?*

Theo: *Yeah, yeah. Because we have our own means of transport. I mean we've got the car there so if I wanted to go to the hospital now, a stroke, or if she wanted to go to the hospital, we're in the car and gone before anybody knows about it. So we are – we depend on each other a great deal because – well there's no kids here and there's no other people and then we tell the neighbours or what have you. But basically we depend on each other.*

Int: *So it's not really something that's ever cropped up that you need to go to other people, be that neighbours or local friends or....*

Theo: *No, no. Only if - one day like the gas was playing up and that's why we've got that monitor up there - we were feeling a bit dizzy and that. But that's the only time – if something happened to the two of us we'd call neighbours in, but basically I look after her and she looks after me.*

Theo, 1st Interview

Despite the fact that Theo and Anne have a large and durable local social network, they do not consider other people as a source of support *per se*. Rather, Theo and Anne rely upon one another rather than upon other people. This relational dynamic and was

highlighted elsewhere in Theo's interviews through reference to their relationship as that of a team:

Then you grow up as a team, don't you? You come together. I mean she knows what's wrong with me and I know what's wrong with her or what's good or what's bad. I feel – well that's it, there are no secrets basically.

Theo, 1st Interview

To describe Theo and Anne's relationship as 'close' would be insufficient – this is a relationship in which the boundaries between two individual subjects is blurred. Theo and Anne's relationship is such that, in terms of social resources, their wider social network is rendered superfluous. Neither looks beyond one another for support or assistance. Theo's example is testament to the fact that focusing upon the quantity of social contacts, or the objective structure of an individual's social network, will lead only to a partial reading of supportive relationships. Rather, understanding supportive practices requires an appreciation of the nuances of specific relationships – their history over the life course, and the institutional frameworks (in this instance marriage) which contribute to their meaning.

Theo's illness is very complex, and his case illustrates that particular health concerns may also be associated with specific supportive requirements. Theo lives with numerous chronic conditions, he has a congenital disability which limits his mobility, and he also suffers the after effects of a number of acute illnesses. This complexity means that Theo faces regular and distinct challenges – his supportive needs reflect this. Anne spoke at length about how she supported Theo, and in doing so, she associated particular illnesses with specific types of support. For example, Anne discussed the issue of accompanying Theo to GP appointments:

Int: *You said that you go together to the GP. Is that something you've always done?*

Anne: *Only since he's had the stroke. Well he never used to go to the doctors. He never used to do – he'd tell me that there's no need to. They found out that he had blood pressure when he was working because you had a medical, didn't you?. [Yeah]. Then he had to go every six months or whatever to the GP. I never went with him then. It's only since he had the first stroke that whenever he's had an appointment - even when he had the chest infection I went in with him.*

Anne, Theo's 1st Interview

Anne makes a clear association between stroke, and the need for her to accompany Theo to medical appointments. In discussing this further, Anne clarified why she considered this necessary:

I asked him if I can go and he said, 'yes, come in with me'. He forgets dates and he'll forget his name and various things.

Anne, Theo's 1st Interview

As a result of a number of 'mild strokes', Theo now experiences certain mild cognitive difficulties; Anne identifies this limitation as requiring a particular supportive response on her part (attending GP appointments with Theo). In abstracting out from this particular example, it is sensible to assume that the forms of support required by people living with multimorbidity will vary according to their particular combinations of illness and disability. Reflecting upon Theo's case, we are reminded as to the heterogeneity of participants in this study. Despite having a number of illnesses in common, each participant also lives with additional chronic and episodic conditions which present a unique set of challenges. In thinking about the experience of social resources during multimorbidity, variety and difference (in terms of supportive requirements) are characteristic, and in this instance, corporal and cognitive needs inform the type of support needed and the way in which it is experienced.

In summarising Theo's case, there are a number of observations which have implications for how we consider social networks and social resources. Specifically, in seeking to understand how an individual is socially connected, we must recognise that the immediate social network is only a partial picture. Theo has very few immediate social contacts of his own, however by virtue of Anne's social network he is very well connected. Accordingly, it is important to consider social connectedness in a way which is not reductive (for example, by depicting social connectivity in singularly quantitative terms, or in terms of social network structure alone).

Theo's case also emphasises that a single relationship within an individual's social network may be responsible for the vast majority of care and assistance. Despite the fact that Theo and Anne are well connected to others, they rely upon one another for support. This affirms the importance of understanding particular relational dynamics within supportive practices.

Finally, Theo's case has highlighted the importance of corporal and cognitive issues in the experience of support and assistance. Anne was able to identify Theo's experience of stroke as requiring a specific supportive response on her part. While supportive exchanges represent complex social practices, it is important to recognise the role of immediate corporal and cognitive needs in shaping these process.

5.4 Discussion

Identifying emergent themes from the preceding case studies is a difficult task. What is clear is that there is huge diversity among participants' experiences of social networks and social resources. Further, it is also apparent that in each case, material and embodied circumstances vary significantly. As a result of this diversity, establishing themes based upon empirical commonalities is problematic. However, in reflecting upon this complexity and diversity, there are a number of important issues raised in terms of how social

networks are conceptualised, and also in relation to how we understand the exchange of social resources.

In terms of conceptualising social networks, this chapter has problematized the notion that social networks may be classified in normative terms. What is meant by this is that seeking to classify participants' social relations and sense of connectedness according to categories or typologies is of limited value. To illustrate this point, we might consider the above cases in relation to some common approaches towards the classification of social networks.

One approach to classifying social networks is according to the geographic proximity of social contacts.¹⁴ Within the cases identified, Isla and Mary have contrasting social networks in this regard. Isla's son lives over 150 miles away, whereas Mary's daughter lives just five miles away. A naïve logic might reason that Isla – given the large distance separating her from her family – might have less opportunity for support and assistance, whereas Mary – by virtue of her daughter living nearby – would be more likely to experience regular support. However, as this chapter has detailed, this does not reflect the ways in which these relationships are experienced. To understanding the ways in which Mary and Isla's children support them, we must consider these relationships through an historic lens. Isla spoke about her son in terms suggestive of a strong and durable relationship. Isla has full confidence that her son will assist and support her in whatever way she might need. By contrast, Mary has little contact with her son, and is unable to rely upon her daughter for support or assistance. Mary believes her daughter will assist her in an emergency, however she does not put her 'to the test'. To understand these issues requires that we examine the history of these relationships, and in particular, the difficult and challenging circumstances faced by Mary's children during their childhood.

¹⁴ This is a common descriptive measure within social network and social capital literature (see Wenger 1992, 1995, 1997).

In light of factors such as this, the logic of geographical classification seems somewhat redundant.

Another way in which social networks are often conceptualised is according to their 'objective' characteristics, for example, classifying individuals as possessing a 'large social network' or 'small social network'. However, the case studies in this chapter highlight the arbitrary nature of such an approach. Theo (by virtue of his wife's social contacts) is among the most socially connected participants in this study, he is in regular contact with a large and diverse array of people. However, we know that Theo's experience of support owes little to the objective size of his social network: his wider social contacts are essentially superfluous. Rather, understanding Theo's social resources requires a close reading of one particular relationship, his relationship with his wife. In a similar fashion, Isla's social network might also be characterised as objectively large. However, Isla's experience of support differs again. For Isla, local friendships are of primary importance, providing her with an extraordinary amount of support and assistance. To grasp the meaning and function of these friendships requires that we consider Isla's social network in a biographical context. Isla's experience of social connectedness is shaped by her 60-year association with the local area and her history of involvement in civic organisations. Here again, attempting to understand these issues by reference to an objective social network characteristic seems a crude logic, and also risks obscuring important nuances in process.

The above examples underscore the fact that, confronted with diversity and complexity, it is not necessarily helpful to classify participants' experiences according to arbitrary variables such as network size, or geographic proximity. This criticism would also be applicable to an approach which sought to explain the same complexity by reference to 'what friends do', 'what family does', or 'the role of neighbours'. Such approaches are problematic because they seek to explain social phenomena using 'realised categories' (Bourdieu; 1996) as explanatory variables, that is, categories assumed to describe social

reality, but which are also constitutive of social reality. To move beyond an understanding of social networks and social resources in reductionist terms requires an appreciation of these social phenomena in terms of social practice (Bourdieu, 1990; Ortner, 1984, 2005). What this requires, practically speaking, is identifying aspects of supportive processes which are seemingly complex or ambiguous, and exploring these factors critically. From this perspective, complexity and diversity should not be seen as being problematic in analytic terms, or as something to be overcome through closer classification. Rather, interrogating this complexity is a constructive enterprise, and the first step towards delivering an account of social resources as social practice. Turning again to the three case studies in this chapter, we might consider what features of these accounts appear, upon first reading, problematic.

The first issue, as has already been identified, regards the dynamics of social relationships in shaping acts of support. This chapter has made the observation that social relationships affect supportive processes, and that important relational dynamics defy simple classification: Mary's daughter does not support her, Theo's wife is the only person supporting him, whereas Isla's neighbour will visit her twice a day, every day. However, if classifying these relationships according to objective or normative (realised categories) characteristics is not productive, how should we consider social networks? The cases in this chapter provided useful insight in this direction. Specifically, social networks should not be considered an immediate or synchronic phenomena per se, rather they are biographically constituted and diachronic. This is a claim which challenges the concept of the social network in objectivist terms. Participants did not discuss their social networks in a manner conveying the immediacy of social relationships, rather other people were discussed in terms of their interlacing biographies, and the ways in which relationships developed over the life course. Further, in further testament against objectivist thinking, the cases in this chapter suggest that we consider social contacts who are not immediately connected (friends-of-friends), as well as appreciating the role of those

people absent through bereavement or loss (for example, Isla's estranged friend). In recognising these issues, we are reminded that a 'social network' is simply a metaphor, used by researchers to evoke a sense of interconnectedness among people. This metaphor, however, also evokes less helpful notions of social relationships as objectively structured, and relationships as immediate and ahistorical. Perhaps a more appropriate way to imagine social networks is according to the convoy model of social relationships (Antonucci and Akiyama, 1991, 1995). The convoy model stresses the ways in which social networks are experienced – in both form and function – as linked to the life course. According to Antonucci (2009) the convoy model 'strongly emphasizes the life-span cumulative aspects of development and the life course situational context' (Antonucci, 2009: 327). Although this concept of social connectedness is but another metaphor, it is a useful one. The convoy model emphasises that individuals live their lives accompanied by a cohort of other people including friends, family, and neighbours. The types of people within an individual's cohort, as well as their significance and roles within relationships, are understood to change as the individual moves through the various stages of life. A particular strength of the convoy model is its sensitivity towards temporality and biography. Further, the convoy model recognises that people of differing ages are, structurally speaking, positioned differently within social, cultural, and economic fields. Most importantly of all, the convoy model resonates with the ways in which participants' in this study interpreted and experienced the social relationships in relation to support and assistance.

Beyond social networks, an area of further complexity has been identified as the meaning attributed to supportive acts. This was evident as each participant discussed support in equivocal or ambivalent terms, and was most apparent where participants framed discussion through the moral dichotomy of dependence and independence. Isla, for example, identified independence as a virtuous characteristic and spoke about the prospect of asking her son for support in negative terms – 'I think it's good for your family

if you can be independent'. Mary alluded to similar issues and identified herself as being 'as independent as I can be'. Theo referred to his relationship with Anne by reference to dependency, and he was keen to highlight the reciprocal nature of their relationship – 'I look after her and she looks after me'. For supportive relationships to be discussed in these terms suggests an important link between support, morality, and identity. This issue requires thorough treatment and is beyond the scope of the immediate discussion. The issue of support, morality and identity will be revisited in Chapter Eight.

A further issue to be highlighted by the above cases concerns the meaning of particular forms of support. Previous attempts to classify social resources and social support have recognised diversity in supportive practices – emotional, appraisal, informational, instrumental support, for example (House, 1981). However, such typologies perpetuate the idea that supportive practices may be understood in terms of the function they fulfil. The case studies presented in this chapter suggest that social resources may not be understood in instrumental terms alone. Isla, for example, spoke about the various different forms of support provided by her neighbour and her experience of support in managing personal finances was particularly telling. Isla spoke about this issue with some enthusiasm and detailed an example where her neighbour assisted her by drawing her pension. However, Isla stated clearly that she did not want the same neighbour to be involved in other aspects of her personal finances – 'I don't want her to have anything to do with that'. This example illustrates the potential for support to be experienced as meaningful in subtle and complex ways. In this sense, the receipt of support is shaped by aspects particular to context, the form of support which is exchanged, and the relationship within which support occurs. What this means, in practice, is that the meaning of a supportive act cannot be understood by reference to its function or outcome alone. Rather, the meaning of supportive acts includes social and/or cultural logics of meaning. This issue – the meaning or 'value' of social resources – will be taken up in chapter Seven.

The aforementioned issues (morality and value in the exchange of social resources) will be addressed in subsequent data chapters (chapters Seven and Eight). However, before these issues may be addressed in full, several conceptual challenges must be outlined and addressed. Specifically, the ways in which morality and value are treated within extant empirical and theoretical literature requires critique, before an appropriate analytic framework may be put forward. The following chapter deals with these issues, and outlines the analytic framework which will be applied in Chapter Seven and Chapter Eight.

Chapter Six: Theoretical review

6.1 Introduction

This chapter represents a pause in the progression of this thesis and will not present participant data. Rather, this chapter presents a discussion of several conceptual and theoretical issues encountered throughout data collection and analysis. The previous chapter (Chapter Five) has gone some way towards describing the complexities inherent in supportive practices during multimorbidity. In doing so, Chapter Five identified two themes (value and morality) which, it has been suggested, are complex and confound normative explanations. This chapter is intended to outline the mode of reasoning through which these issues were confronted during analysis, and to introduce a conceptual framework which will be applied in subsequent results chapters.

This chapter is structured into two parts. The first part of this chapter addresses deficiencies and limitations within dominant conceptual apparatuses. Specifically, the conceptual lineage of social capital will be outlined, with the detrimental influence of individualist social exchange theory and Rational Choice Theory (RCT) made clear. In the second part of this chapter, an alternative body of theoretical literature will be presented. This parallel theoretical stream – gift exchange literature – will be outlined in terms of its foremost tenets, and with regard to the particular issues of value and morality. It will be concluded that by incorporating insight from gift exchange literature, our understanding of supportive practices may be improved.

6.2 Social capital's conceptual lineage

The literature review of this thesis has outlined the development of social capital theory throughout the 1990s, and has identified the influence of three contemporaneous authors: James Coleman, Robert Putnam, and Pierre Bourdieu. Within social science and health literature, it is the work of Coleman and Putnam which is privileged, with Bourdieu's broader social theory largely ignored (Moore 2005, 2006; Fine, 2010; Fine and Milonakis

2009).¹⁵ As such, in terms of critiquing contemporary perspectives, it is the work of Coleman and Putnam which is of primary concern to this thesis. To understand the contribution of these authors, it is helpful to recognise a number of important theoretical antecedents. Recognising these antecedents is helpful in explaining the weaknesses and limitations typical in latter social capital perspectives. The following section locates the social capital theories of Coleman and Putnam against wider historical developments in social theory, before proceeding to detail alternative perspectives.

6.2.1 The network perspective

Social capital is principally a product of 1990s social theory; however, its theoretical taproots are to be found in 1960s American sociology and a time when Parsonian functionalism prevailed. Against the dominant perspective of the day – structural functionalism – emerged critiques which questioned the ‘oversocialized conception of man in modern sociology’ (Wrong, 1961). Such perspectives argued against approaches which, in their view, depicted social actors as overly-suborned to the values and norms of stable and integrated social systems.¹⁶ Anglo-American sociological thought developed in accordance with this critique – against forms of sociological holism, and in favour of theoretical perspectives which privileged the role of the individual as self-aware, deliberative, and skilled in the practices of everyday life.

One such development in post-Parsonian social theory was a perspective which has been termed the ‘network approach’ (Crossley, 2010). Proponents of the network approach accepted the critique of ‘oversocialized’ functionalism (Wrong, 1961), and yet, were uncomfortable with the most immediate alternative – individualism qua neoclassical economics (Scott, 1995). A key proponent of the network approach was Mark

¹⁵ Moore (2005, 2006) has described citation patters within health literature. Using bibliometric methods Moore has demonstrated that Coleman ranks highest (in terms of a citation count), followed by Putnam, with Bourdieu not featuring in the 10 most cited social capital references.

¹⁶ Archer (1995) provides a useful synopsis of this moment in the history of social theory.

Granovetter, whose work – including the strength of weak ties (1973) and the concept of embeddedness (1985) – continues to influence contemporary research and scholarship. Granovetter is exemplary of the network approach in his attempt to transcend both functionalist and individualist positions. To do this, Granovetter employed the concept of the social network as a structuring feature of everyday life:

What I came to argue is that one has to thread one's way between these under and over-socialized views by seeing that all economic activity is in fact embedded in complex, ongoing networks of social and economic relationships, and the trust that makes such activity possible, but also the malfeasance that can bring it to a halt, can only be explained by a close analysis of how people function in such networks (Granovetter, 1990: 14).

The notion of individuals as *networked individuals* gained recognition and support in subsequent years, facilitated by a theoretical landscape wherein economic sociology – exemplified by Becker (1976) – and behavioural sociology – championed by Homans (1974) – held sway. Lin, Dayton, and Greenwald (1978), following Granovetter, were among the first to conceptualise social resources as a form of personal capital provided by social networks. Influenced by Granovetter and Homans, these authors conceived of individuals as embedded within networks of personal and professional relationships which were understood to afford various social resources. In this regard, it is interesting to note that early formulations of social resources bear striking affinities with latter developments in social capital theory:

The concept of social resources encompasses two components: social relations and the resources embedded in positions reached through such relations. The concept contrasts and complements the concept of personal resources... While personal resources involve the individual's wealth, status, and power, social resources are

embedded in the positions of contacts an individual reaches through his social network (Lin, Vaughn, and Ensel, 1981: 395).

Lin, Vaughn, and Ensel (1981) were concerned – as was Granovetter (1973) – with understanding how individuals attain occupational status and professional achievement. In this context, social resources were taken to include both the material (wealth) and symbolic (prestige) resources afforded by the individual's membership of a social network.¹⁷ Elsewhere, Lin (1982) provided the definition of social resources as 'material or symbolic goods', and so affirmed the notion of social relationships as a form of personal capital in both materialist and idealist terms.¹⁸

Lin and Granovetter have been influential in advancing the study of social relationships according to the network perspective; in this direction, the network perspective has been productive in addressing some of the weaknesses inherent in both individualist and collectivist positions. Clearly, the network perspective is not a novel theoretical position; the concepts of social networks and community have been considered within parallel schools of social theory (symbolic interactionism, for example). However, authors such as Granovetter and Lin have influenced the ways in which social networks are conceptualised as a structuring feature of everyday life (this being the enduring influence of the network perspective). In this respect, the legacy of the network approach has been to consider social relationships in instrumental terms. This is apparent in the way that social networks are presented as facilitating (or limiting) the accomplishment of a particular social action or behaviour of interest. Indeed, the very notion of social resources and social relationships as a form of personal capital pre-supposes the context of goal-oriented action. Whilst this is an important aspect of social relationships (and one which this thesis would not wish to discount), it is the position of this thesis that focusing upon

¹⁷ Lin's formulation of symbolic goods – prestige and status – are analogous with material goods and as a form of personal capital.

¹⁸ Lin would later become a key figure in social capital theory; see, for example *Social Capital: A Theory of Social Structure and Action* (Lin, 2001)

the role of social relationships in the accomplishment of goal-oriented action is reductive, and limits our understanding of co-operation and collaboration during the illness experience. This point will be revisited, and consequences made clear, throughout this chapter.

6.2.2 Individualist social exchange

A further body of literature which has influenced contemporary perspectives is social exchange theory.¹⁹ Social exchange theory, much like the network perspective, emerged during the 1950s and 1960s in reaction to ‘overly-socialized’ modes of social theory. In particular, social exchange theory may be recognised as a transatlantic riposte to Lévi-Strauss’ *The elementary structures of kinship* (1969). Lévi-Strauss had detailed a theory of general exchange (based upon the exchange of women within pre-capitalist societies) in what remains an epitome of structuralist anthropology. At the forefront of the individualist response was Homans (1950, 1974), whose work is now synonymous with social exchange theory.

Homans extended the logic of exchange beyond tangible objects to include all forms of social activity. Homans’ most characteristic contribution, however, was to critique the role of culture in exchange, and to proffer a theory based upon utilitarian logic. Ekeh (1974) summarises the central tenets of Homans’ social exchange theory as follows:

- 1) *Social exchange occurs within face-to-face relations*
- 2) *Social exchange may be understood as restricted exchange, limited to two individuals*
- 3) *Social exchange privileges ‘human motivation’ based upon psychological and economic needs*
- 4) *The items or actions exchanged are considered in terms of utilitarian value*

¹⁹ Coleman (1988) has described social exchange theory as ‘pathbreaking’ in relation to his own model of social capital.

(Ekeh, 1974)

In contrast to Lévi-Strauss, Homans' social exchange theory was markedly individualist, and stressed the role of utilitarian action and 'human motivation'. Ekeh (1974) provides an excellent review of Homans' contribution in relation to the Structuralist position:

In no other social exchange theorist is there such an explicit combination of psychology and economics. Homans stands as an 'individualist-orientated', or, in his own words, an 'individual self-interest theorist' par excellence... Lévi-Strauss' position retains the French collectivist orientation, while Homans advocates the individualistic orientation in social exchange (Ekeh, 1974: 87).

Following Homans, social exchange theory developed through the work of Blau (1964), who sought to refine and advance a social exchange theory which further incorporated marginal economic theory and psychological behaviourism. The results were a reading of human agency and social action wherein psychological and economic reasoning prevailed:

Blau's social exchange theory is eminently individualistic – indeed it is nearer Spencerian and Frazerian individualism in its emphasis on economic self-interest as the motive for social action than Homans' conditioned behavioural individualism (Ekeh, 1974: 167).

For the purposes of this thesis, it is sufficient to recognise social exchange theory as a perspective that is polemically opposed to Lévi-Strauss' structuralism; social exchange theory is influential in its promotion of methodological individualism. Further, social exchange theory has played an influential role in advancing micro-economic and psychological models of agency in social exchange; the individual's attachment to society, their membership of social groups, and socio-cultural factors are largely dismissed. This mode of social theory has influenced social capital, and continues to influence approaches

which conceptualise social relationships and social resources as a form of personal capital: this claim will be supported in the following section.

Both the network perspective and social exchange theory developed with a degree of independence. However, throughout the late 1980s and 1990s various attempts were made to synthesise both approaches into a unitary social theory. The rationale for this was the apparent synergy between network perspectives upon social structure, and the models individualism advanced by social exchange theory. This synergy was noted by Cook and Whitmeyer (1992), who highlighted complementarities between both positions:

Much convergence exists between exchange theory and network approaches to social structure... Exchange theory and network analysis both conceptualize social structure as a configuration of social relations and positions... Exchange theory and network analysis are based on similar conceptions of the actor (Cook and Whitmeyer, 1992: 110).

In the above quotation, the authors identify that both approaches share a common conceptualisation of social structure as the immediate social relationships between actors; further, both envisage social networks as working to constrain and/or provide possibilities for social action. Both approaches treat the individual in a similar fashion; social exchange theory privileges individual and psychological models of behaviour, and this position is accommodated within network perspectives. It is towards social capital that this discussion will now turn.

6.2.3 Social capital

Social capital, as developed by Coleman and Putnam, may be seen as the theoretical progeny of social exchange theory and the network perspective.²⁰ Social capital depicts social structure in a fashion markedly similar to the network perspective: networks of

²⁰ Each author's respective definition of social capital has been provided in the literature review of this thesis.

social or institutional relationships constrain, or provide opportunity for social action. The network perspective is apparent in the ubiquitous application of social network terminology in social capital texts. The influence of social exchange theory is less conspicuous; however, due to the fact that social exchange theory concerns fundamental aspects of human agency and social action, its influence is arguably more problematic.

Coleman – the most cited social capitalist within health literature (Moore, 2005. 2006) – has identified social exchange theory as ‘pathbreaking’ in the development of his own social theory (Coleman, 1988). In this respect, social exchange theory laid important conceptual groundwork for social capital in considering interaction, co-operation and social exchange according to individualist modes of agency and social action. Theories of social capital address these issues from a similar position, and the most influential exponents of social capital (Coleman and Putnam) demonstrate clear propensities towards methodological individualism and micro-economic theory. For Coleman, as for Homans and Blau, individuals are understood to be rational and deliberative social actors, with social action proceeding according to the individual’s pursuit of marginal benefit. In this regard, Coleman’s social capital theory is staunchly individualist:

I will use the conception of rationalism employed in economics, the conception that forms that basis of the rational actor in economic theory. This conception is based on the notion of different actions (or, in some cases, different goods) having a particular utility for the actor and is accompanied by the principle of action which can be expressed by saying that they actor chooses the action which will maximise utility’ (Coleman, 1990: 14).

A similar rationalist individualist perspective is apparent in Putnam’s social capital theory (Putnam, 2000). Putnam is cited regularly as demonstrating communitarian sensibilities; however, he shares a foundational social theory similar to that of Coleman. For Putnam, ‘systems of reciprocity’ form the cornerstone of social action and co-operation. This

concept – systems of reciprocities – appears at first glance to be intrinsically collective. However Putnam's reading of reciprocity is influenced heavily by Taylor (a key theorist in RCT and game theory). In explaining his theory of social capital, Putnam cites Taylor at length:

Each individual act in a system of reciprocity is usually characterized by a combination of what one might call short-term altruism and long-term self-interest: I help you out now in the (possibly vague, uncertain, and uncalculating) expectation that you will help me out in the future. Reciprocity is made up of a series of acts each of which is short-run altruistic (benefiting others at the cost of the altruist), but which together typically make every participant better off (Taylor, quoted in Putnam 2000:134).

For Putnam, the self-interested individual, whilst less pronounced than in the social capital of Coleman, remains at the heart of explaining actions such as co-operation and collaboration within social networks. The limitations of this assumption will be addressed shortly; however, a further consequence of this position should be highlighted.

The RCT foundations of social capital theory influence, detrimentally, the ways in which social networks are conceptualised. Specifically, for social capitalists (as with earlier network perspectives), social relationships are considered in a reductive manner according to their role in the accomplishment of goal-oriented action. Coleman, for example, assumes this position in considering social relationships as a form of personal capital:

We begin with a theory of rational action, in which each actor has control over certain resources and interests in certain resources and events... social capital constitutes a particular kind of resource available to an actor (Coleman, 1988: 98).

As a consequence, social capital has a tendency towards treating social relationships and concomitant acts of support, assistance and co-operation in functional or utilitarian terms.

Here, parallels with earlier network approaches (Granovetter, 1973; Lin, Dayton and Greenwald, 1978) are clear, as the complexities of social exchange are reduced to a utilitarian reading of social relationships:

Social capital is defined by its function... Like other forms of capital, social capital is productive, making possible the achievement of certain ends that in its absence would not be possible (Coleman, 1988: 93).

Such an approach to the study of social relationships is problematic for a number of reasons (Fine 2008, 2010). Most limiting with regard to this thesis, however, is that a utilitarian approach neglects both the affective (emotional) and socio-cultural (meaningful) dimensions of social relationships. It is the position of this thesis, that such a blinkered reading of relationships is detrimental to our understanding of support and assistance during illness.

These limitations are not unexpected, however, and may be explained by reference to the established critique of RCT and methodological individualism. For the purposes of this chapter, the following statement from Archer (2012) summarises this critique, which may also be read as a critique of social capital. Archer takes aim at the prototypical vision of the individual qua RCT, *Homo economicus*:

Homo economicus, the model most explicit in mainstream economics and Rational Choice Theory... contributes nothing to the 'common good', unless by accident, and is unmoved by 'his' social relations... Homo economicus is an impoverished notion of the human being, which cannot cope with our capacity to transcend instrumental rationality and to devote ourselves to concerns that are not a means to anything beyond them, but are commitments that are constitutive of who we are – be they our children, Church, career, community or cause. These relations are the basis of our personal identities and none of them can be reduced to instrumental means-ends

relationships, assumed to leave us 'better off' relative to some notion of future 'utility'
(Archer, 2012: 2).

Extending this insight, this thesis takes the position that social capital (or any approach which applies latently similar concepts of agency and/or social action) is insufficient with regard to the complexities of co-operation, collaboration and support during illness. As suggested by Archer (2012), the study of such phenomena must begin by recognising that individuals often transcend instrumental rationality and devote themselves to actions and causes that confound, even contradict, instrumental logic. Further, as is intimated by Archer (2012), the way we understand individuals in relation to their social network should proceed by placing the formation of Self at the core of our analysis. Actions of support and assistance (particularly those which occur during the experience of illness) are likely to involve affective, social and cultural complexities which shape fundamentally the relation between individual and the Self. In recognition of these observations, alternative modes of social exchange and social resources must be considered.

6.3 Gift exchange: an alternative approach

In seeking to understand the exchange of social resources during illness, this thesis considers alternative traditions of social exchange. One body of literature which is particularly illuminating is the social anthropology of gift exchange. The field of gift exchange consists of a rich and diverse array of contributions; however, for the purposes of this chapter, a select few sources are sufficient to address the limitations identified in the above discussion.

6.3.1 Mauss' gift

Perhaps the seminal text in gift exchange literature is Mauss' (1922 / 2011) essay *The Gift*. Mauss was concerned with documenting the cultural intricacies of exchange in 'traditional' or pre-capitalist cultures. Mauss provided a comparative analysis of gift exchange in Polynesia, the Pacific Northwest, and Melanesia. In doing so, Mauss detailed

the exchange of objects and actions between individuals, within communities, and through ritual practices. To summarise, Mauss described the ways that such exchanges were shaped by rich and stratified socio-cultural frames of meaning. In this sense, Mauss' fundamental contribution was to demonstrate that gift exchange may not be considered analogous to commodity exchange. Rather, Mauss illustrated that practices of gift exchange followed distinct logics of reason; these logics being ascertained through non-utilitarian and collectivist modes of analysis. In this sense, Mauss' preliminary statement may be seen to be emblematic of his broader social theory:

In systems of the past we do not find simple exchange of goods, wealth and produce through markets established among individuals. For it is groups, and not individuals, which carry out exchange, make contracts, and are bound by obligations (Mauss, 2011: 3).

Mauss' study of exchange is, in comparison to contemporary social exchange theories, markedly collectivist. In this respect, Mauss (and gift exchange theorists generally) provide a theoretical outlook which is polemically opposed to social exchange theory. Since publication, *The Gift* (1922 / 2011) has generated countless secondary analyses and critiques. However, for the purpose of this thesis, Mauss aids the analysis of social resource exchange in two ways.

Firstly, Mauss highlighted the role played by morality in exchange, and made the famous observation that gift exchange was governed by codes of moral obligation, admonishment, and sanction:

...although presentations and counter presentations take place under a voluntary guise they are in essence strictly obligatory, and their sanction is private or open warfare (Mauss, 2011: 3).

Similar observations have been made subsequently within individualist social exchange (contemporary perspectives rely upon the concept of reciprocity). However, Mauss'

analysis is consistent with a Durkheimian perspective according to which morality is considered a social fact extraneous and irreducible to the individual (Zigon, 2008).²¹ Mauss identified three forms of moral obligation: the obligation to give, the obligation to receive, and the obligation to repay. In this regard, Mauss encourages us to consider moral action which, in the first instance, appears at odds with instrumental rationalism (the obligation to receive, for example, is absent in analyses which rely upon RCT). Further, Mauss – following Durkheim – makes the fundamental assertion that morality must be considered in terms of the individual's attachment to society (Durkheim, 1961). In this sense, Mauss promotes an understanding of social exchange which is sensitive towards aspects of morality that are socially and culturally constituted (rather than morality in its individualist contractarian guise, such as reciprocity). It should be pointed out that the Maussian perspective does not escape critique, and Mauss may be subjected to the criticisms directed at collectivist social theory more generally (Archer, 1995; Zigion 2008). Despite this, however, Mauss serves as a useful counterpoint to the individualist reading of morality.

A second insight provided by Mauss concerns the meaning, or value, of objects and actions exchanged as gifts. Mauss observed that gift exchange could not be explained by reference to the economic worth of the objects exchanged:

What they exchange is not exclusively goods and wealth, real and personal property, and things of economic value. The exchange rather courtesies, entertainments, ritual, military assistance, women, children, dances, and feasts (Mauss, 2011: 3).

For Mauss, the value of such objects could only be appreciated (and the practices of exchange understood) once their social and cultural meaning was recognised. In

²¹ Durkheim was Mauss' uncle, academic patron, and collaborator.

exploring such cultural logics of value, Mauss prefigured latter social theorists in adopting the semiotic terminology of signification:

Each of these precious things... has a productive capacity within itself. Each, as well as being a sign and surety of life, is also a sign of surety of wealth, a magico-religious guarantee or rank and prosperity (Mauss, 2011: 43).

In this sense, Mauss delivers an analysis of exchange which begins to incorporate symbolic and semiotic logics of value. Of immediate relevance, however, is the fact that Mauss' value is pluralist. Accordingly, the meaning of objects and actions are understood by incorporating economic value alongside logics of meaning which are socially and culturally constituted: rank, status, vitality, for example.

Clearly, the empirical subject matter of Mauss' fieldwork is somewhat remote from that of this thesis. However, Mauss' insight remains productive given the predominance of individualist modes of exchange (including social capital and approaches which consider social networks in instrumental terms). It has been suggested (above) that individualist modes of social exchange demonstrate a predilection for utilitarian, functional and economic reasoning. The Maussian perspective reminds us that such approaches will only ever deliver a partial reading of social exchange. For the purposes of this thesis, Mauss acts as a polemical counterweight to individualist social exchange perspectives. The following two sections outline further the contribution made by gift exchange, and will detail the ways that morality and value are addressed in the data chapters which follow (Chapters Seven and Eight).

6.4 Moral economy

The concept of a moral economy is common in gift exchange theory (Carrier, 1995) and follows Mauss' observation that social exchange occurs under a range of moral precepts: the obligations to give, to receive, and to repay. To speak of morality in terms of obligations is, perhaps, somewhat outmoded; the treatment of morality in the social

sciences has developed (since Mauss) according to wider trends in social theory.

Addressing morality remains vital, however, as it represents an indissoluble aspect of social action and is tied intimately to the formation of Self (Sayer, 2011).

Morality has long held a place in the analysis of social exchange. However, in recent decades, approaches to morality have been dominated by the 'moral mechanism' of reciprocity. Reciprocity is recognised widely as a fundamental constituent of social relationships; indeed, reciprocity is likely to be as close to a culturally universal cultural motif as it is possible to find (Neusner and Chilton, 2008). However, the mode of reciprocity that has come to bear in recent years is marked indelibly by the shortcomings of individualist social exchange. As such, whilst reciprocity should be recognised as an important feature of our moral evaluations, from an analytic perspective, reciprocity must be examined critically.

Emblematic of the individualist mode of reciprocity is that advanced by social capital theory. In this regard, there is no clearer expression of individualist morality than reciprocity according to Putnam (2000):

The touchstone of social capital is the principle of generalized reciprocity – I'll do this for you now, without expecting anything immediately in return and perhaps without even knowing you, confident that down the road you or someone else will return the favour (Putnam, 2000: 134).

Putnam's reciprocity captures two aspects of moral action which require consideration. Firstly, in Putnam's scheme there is a sense that reciprocity binds individual social actors to specific acts of co-operation; reciprocity functions as a form of micro-social-contract between definite individuals. In this mode, individuals are morally compelled to reciprocate a specific act in relation to a particular individual. Secondly, the notion of 'generalised reciprocity' assumes that individuals experience a similar contractarian ethic to non-specified persons, or to a wider community of persons. Accordingly, the act of

reciprocation need not be tied to specific antecedent acts or particular individuals, but occurs under the influence of a norm of deferred reciprocation from others.

At first reading, Putnam's conceptualisation of reciprocity seems sensible, even appealing. However, given what has been argued (above) as to the limitations of social capital theory – specifically, the limitations of RCT – it is unsurprising that morality qua reciprocity should involve a number of unwelcome assumptions. These assumptions are detrimental in (at least) three respects.

Firstly, whilst couched in communitarian language, Putnam's reciprocity retains the tacit assumption that people are motivated to act morally according to the prospect of marginal gains. Putnam states clearly that people who engage in ethical action do so because they calculate some form of immediate or deferred benefit (someone else will do something for them). This is an insufficient reading of individual motivation, and is susceptible to the same critique which has been levelled against models of human agency premised upon RCT (such as social capital). Secondly, by focusing solely upon instrumental or goal-oriented action, this mode of reciprocity is limited in its conceptualisation of what may constitute moral action. This contractarian form of reciprocity tends to neglect forms of action which are meaningful or hermeneutically oriented: it is weaker for this. Finally, the above formulation of morality fails to address the fundamental link between ethical action and the formation of Self; this is perhaps its most significant shortcoming.

To highlight these issues as characteristic of individualist exchange, we might contrast Putnam's reciprocity with Iris Murdoch's sentiment that 'our [moral] actions are like ships which we may watch set out to sea, and not know when or with what cargo they will return to port' (Murdoch, 1962: 152). Murdoch's reciprocity consists in the absence of rationally calculating individuals, and recognises the meaning of benevolence and co-operation as linked to faith and abandon. Such a perspective stands in stark contrast to Putnam's, and

makes plain the impoverished nature of morality when viewed through an individualist rationalist lens.

These limitations are characteristic of individualist readings of morality, and have real implications for the conduct of health research. In reviewing the application of reciprocity in health research, Abbot and Freeth (2008) lament the confused and uncritical use of the term. The authors note that the concepts of reciprocity, generalised reciprocity, and altruism are widely deployed with little meaningful distinction. Further, it is also noted that the so called 'norm of reciprocity' is often elided with other norms more closely associated with social control and institutional roles.²² Within health literature, the logic of social capital (and RCT generally) endures in the assumption that people act in an ethical or moral way because it is in their interest to do so. While this logic may be appropriate for certain subjects of sociological inquiry – professional status attainment, for example (Lin, Vaughn, and Ensel, 1981) – it is patently insufficient to capture the depth of moral crises and suffering which have been identified as a part of the experience of illness (Frank, 1995; Kleinman, 1988).

This thesis argues that people act ethically during the receipt of social resources due to moral precepts that are concerned more with the fundamental human condition than they are with instrumental action. A form of reciprocity will be among these precepts; however, questions as to why people 'do good' or do 'the right thing' during the receipt of social resources cannot be answered by reciprocity alone. This thesis will approach reciprocity as a component of a larger and more complex moral imperative. In doing so, morality will be treated in terms which appreciate meaningful (in addition to instrumental) reason (Sayer, 2011), as well as recognising the fundamental associations between morality, social action, and Self (Taylor, 1992).

²² These norms may also be 'moral norms', but they are not a norm of reciprocity.

6.5 Value

Each of these precious things... has a productive capacity within itself. Each, as well as being a sign and surety of life, is also a sign of surety of wealth, a magico-religious guarantee or rank and prosperity (Mauss, 2011: 43).

In reiterating the above passage from Mauss, we are reminded that objects and actions exchanged outside of commodity exchange do not conform to economic logic. Rather, as Mauss observed, to understand social exchange it is necessary to appreciate the relational and socio-cultural significance of that which is exchanged. This insight is also relevant to the exchange of supportive acts, and it is useful to consider the value of social resources in a similar fashion. Incorporating insight from alternative theories of value has the potential to further our understanding of social resource exchange. For the purpose of this thesis, one useful contribution is that of Baudrillard's (1981) typology of value.

To contextualise this typology briefly, during this point in Baudrillard's output he was engaged in an attempt to ally Marx's writings on political economy with French cultural theory (particularly the cultural semiotics of Barthes). In a somewhat neglected volume of essays – *Towards a Critique of the Political Economy of the Sign* – Baudrillard blends aspects of political economy with his burgeoning interests in post-structuralism.

Throughout this volume of essays, Baudrillard takes up Mauss' observations concerning value in gift exchange, and applies this reasoning to the exchange of objects, actions, gestures, and signs within advanced capitalist societies. In doing so, Baudrillard applies a sophisticated theory of culture, and addresses issues which are particular to capitalist societies.

Baudrillard contends that in modern capitalist societies, objects of exchange are subject to four distinct logics of value. Accordingly, the meaning of exchange may be understood as the intersections of use-value, exchange-value, symbolic-value, and sign-value. Stated simply, use-value pertains to a functional logic, whilst exchange-value relates to normative economic logic. In this regard Baudrillard drew upon Marx's writings on commodity

exchange.²³ Sign-value and symbolic-value are the incorporation of Maussian principles of semiotic and symbolic logics of value. For Baudrillard, symbolic-value and sign-value are necessary to explain dynamics of exchange where use-value and exchange-value are erroneous or irrelevant.

This thesis adopts a modified version of Baudrillard's (1981) typology in analysing the meaning of supportive exchanges. The following two sections will detail further symbolic and semiotic logics of value.

6.5.2 Symbolic-value

Symbolic-value is an enduring theme within gift exchange and refers to the inalienability of gifts. Mauss made the observation that 'objects are never completely separated from the men who exchange them' (Mauss, 2011:31). Later gift exchange theorists have developed this observation, and have identified parallel and contrasting aspects of gifts and commodities. In this regard a defining feature of commodity exchange is the interjection of

²³ Baudrillard recognised Marx's definition of use-value as: 'The use-values of commodities provide the material for a study of their own, the science of commodities. Use-value realizes itself only in use or in consumption' (Marx, 1976: 7). Similarly, exchange value was appropriated by Baudrillard as it had been presented by Marx: 'Exchange-value appears first of all as quantitative relationship, the proportion in which use-values of one kind are exchanged for use-values of another kind, a relationship which constantly changes in accordance with time and place.' (Marx, 1976: 7). The relationship between use- and exchange-value being the fascination of both authors: 'The commodity is immediate unity of use-value and exchange-value, thus of two opposed entities. Thus it is an immediate contradiction. This contradiction must enter upon a development just as soon as it is no longer considered as hitherto in an analytic manner (at one time from the viewpoint of use-value and at another from the viewpoint of exchange-value) but is really related to other commodities as a totality' (Marx, 1976: 40). However, where Baudrillard and Marx part company is in terms of their conceptualisation of 'needs'. Marx was somewhat dismissive of the concept of human need in exchange: 'The commodity is first an external object, a thing which satisfies through its qualities human needs of one kind or another. The nature of these needs is irrelevant' (Marx, 1976: 7). However, for Baudrillard, human needs – or rather the ideological genesis of needs – formed the basis of a critical political economy infused with post-structuralist critique. Hence, Baudrillard termed this project a critique of the political economy of the sign.

money. In commodity exchange, money serves to alienate the object of exchange from the seller, allowing the object to be appropriated by the buyer. Gift exchange, by contrast, is defined (in part) by the absence of direct remuneration (monetary or otherwise); for this reason, gift exchange has been termed 'symbolic exchange' (Baudrillard, 1981). During symbolic exchange, because money does not interject, the object of exchange is inalienable from the giver. The phenomenological outcome of this inalienability is that gifts are symbolic of the giver or the relationship between giver and receiver. It is this meaning which is attributed to symbolic-value.

To develop this logic clearly a further example is useful. As a commodity, objects and actions become alienated from those persons involved in exchange: the social relationship does not inhere in the commodity itself. As Carrier (1991) suggests:

In commodity relationships people think of objects as abstract bundles of utilities and values that are precisely not unique...The buyer of a thousand barrels of Brent crude oil, an ounce of gold, a Baby Ruth candy bar, is satisfied with any item that meets the requisite criteria, because each is freely substitutable within its class (Carrier, 1991: 127).

The value of the commodity is, relatively speaking, unaffected by the relationship within which it is exchanged; commodities are interchangeable, fungible, and (in theory at least) their value is equivalent to any other identical commodity. By contrast, objects exchanged as gifts are defined by the relationships within which they are exchanged; the identities of giver and receiver are paramount in defining this meaning. Baudrillard (1981) provides a colourful illustration of symbolic-value in the context of a wedding ring exchanged between two lovers. Wedding rings are, to varying degrees, subject to all forms of value – their use-value may be relatively insignificant, while their exchange-value great (in monetary terms). However, understanding the meaning of the ring requires that we appreciate its symbolic-value:

This is a unique object, symbol of the relationship between the couple. One would neither think of changing it (barring mishap) nor of wearing several... Fashion plays as negligible a role at the strictly symbolic level as at the level of pure instrumentality (Baudrillard, 1981: 66).

The wedding ring is symbolic of the relationship between the couple. This symbolic quality is, in part, a socio-cultural referent (signifying betrothal to others). However, to those involved in exchange, the meaning of the ring concerns, primarily, the relationship within which it is exchanged. It is this symbolic-value which distinguishes the ring given in symbolic exchange from the ring exchanged as commodity: the ring, as an object, becomes unique.

In relating this insight to a reading of social resources, it is useful to incorporate the logic of symbolic-value into analysis. What this means, practically speaking, is attending to the social relationships within which social resources are exchanged, and considering the ways in which relationships give meaning to acts of support. These issues will be developed further in Chapter Seven through the analysis of participant data.

6.5.3 Semiotic-value

In addition to symbolic-value, Baudrillard posits that objects of symbolic exchange are subject to sign-value. For Baudrillard, sign-value refers to a logic of signification, and concerns the meaning of an object, act or gesture within a given cultural field.²⁴ To illustrate sign-value, Baudrillard gives the example of a painting sold at auction.

Baudrillard suggests that the painting may be subject to all value forms (exchange-value being paramount in the auction house). However, if, when the painting is sold, it achieves a price which makes it *the most expensive painting in the world*, then the painting assumes a particular sign-value. Once the painting becomes *the most expensive painting*

²⁴ Baudrillard does not cite Barthes directly, but his interpretation of sign-value bears a close likeness to that of Barthes' social semiotics as in *Mythologies* (1972).

in the world, it then signifies meanings such as prestige, status, and wealth. Whilst these values may be secondary to the painting's exchange-value, Baudrillard contends that they must be appreciated if the value of the painting and the dynamics of exchange are to be understood.

This insight – that actions, gestures, and objects signify meaning in cultural terms – is widely accepted within various social scientific perspectives. One such perspective is that of cultural anthropology. Geertz (1975), in particular, has argued productively that interpretive approaches must recognise the role of cultural semiotics in shaping individual meaning and social processes.²⁵ Such an approach requires that the analysis of phenomenological descriptions, acts, and gestures, be theorised in terms of their cultural significance (that is to say: what these phenomena signify within given 'webs of [cultural] significance'). In relating this insight to the exchange of social resources, it is important to consider how acts of support and assistance might be interpreted as culturally significant. Culturally constituted meaning may, of course, be experienced negatively: whilst Baudrillard discussed prestige, wealth and status, support may also signify failure, deviance or other unfavourable states. In this sense, identifying the form and content of semiotic-values is important because these meaningful significations are likely to play a central role in shaping the individual's experience of supportive practices. These issues will be developed further with participant data in Chapter Eight.

In summarising symbolic-value and semiotic-value, these concepts may be understood as the meaning of a social exchange once use-value and exchange-value are bracketed-out of consideration. Symbolic-value refers to the inalienable quality conferred upon

²⁵ Geertz's interpretive semiotics builds upon Weber's conceptualisation of meaningful action. As Geertz states: 'The concept of culture I espouse... is essentially a semiotic one. Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning. It is explication I am after, construing social expressions on their surface enigmatical' (Geertz, 1975: 5)

supportive acts by the social relationship within which they exchanged. Semiotic-value refers to significance in cultural terms. These logics of value will be incorporated alongside the use- and exchange-value in the following chapter.

6.6 Implications for this thesis

The preceding chapter (Chapter Five) identified two issues – value and morality – which, it was suggested, are not sufficiently conceptualised within theory assumed in health research. In tracing the conceptual lineage of social capital, it has been argued that approaches to the study of social networks and social resources (as a form of personal capital) often suffer from an impoverished conceptualisation of human agency, and an understanding of social action which privileges instrumental or goal-oriented action.

Against this, this chapter has presented an alternative approach to social exchange: gift exchange. It has been argued that gift exchange contributes more sophisticated readings of value and morality; the ways that these factors are to be addressed has been outlined in a preliminary fashion. This thesis will return now to participant data, and will expand upon the concepts introduced in this chapter.

Chapter Seven: The value forms of social resources

... labour in so far as its results are use-values is distinct from labour in so far as its results are exchange-values (Marx, 1859: 8).

Each of these precious things... has a productive capacity within itself. Each, as well as being a sign and surety of life, is also a sign of surety of wealth, a magico-religious guarantee or rank and prosperity (Mauss, 2011: 43).

... objects are never completely separated from the men who exchange them (Mauss, 2011: 31).

7.1 Introduction

This chapter takes up the question as to how social resources are experienced as meaningful social actions, and how this meaning affects and shapes the social practice of giving and receiving support during illness. As has already been identified, there is a tendency within existing literature to conceptualise social resources in a somewhat one-dimensional manner, according to the function they fulfil (House, 1981; Van der Gaag and Snijders, 2005, 2008 ; Webber and Huxley, 2007). Chapter Five detailed three participant cases, and suggested that an instrumental or utilitarian perspective fails to appreciate important aspects of the experience of support. In the chapter immediately preceding this (Chapter Six), it was argued that these limitations are in fact the result of latent theoretical assumptions (concerning individualist social exchange, and utilitarian readings of social networks); this chapter applies a pluralist reading of value to deliver a more perceptive reading of meaning.

The above quotations encapsulate the conceptual framework that will follow. Both Marx and Mauss were concerned with the ways in which objects and actions came to be

realised as valuable in the form of commodities and gifts.²⁶ For Marx, the notions of use-value and exchange-value were central to understanding the meaning of labour as a commodity in the capitalist mode of production. Mauss' project, by contrast, concerned 'traditional' societies and the meaning of objects and actions exchanged as gifts. This chapter adopts concepts emanating from these authors, and in particular, the writings of Baudrillard (1981) who incorporates aspects of both positions. Accordingly, this chapter explores the ways in which supportive actions may be understood by the following modes of value:

- Use-value
- Semiotic-value
- Symbolic-value
- Exchange-value

In the sections which follow, participant data will be presented and each logic of value will be addressed in turn. Finally, this chapter will conclude by illustrating how these four value forms coalesce and intersect during supportive practices in what will be termed an *interpretive economy of meaning*.

²⁶ I use the terms 'value' and 'meaning' interchangeably. Graeber (2001) provides an excellent synthesis of the various ways in which 'value' has been conceptualised across the social sciences. Accordingly, value is addressed in different ways: in economics, value is treated generally in normative pecuniary terms; sociology has traditionally approached value in terms of the value(s) concerning what is good, proper or desirable in human life; finally, value in a linguistic sense which, following Saussure (1966) might simply be termed the 'meaningful difference' between sound images and their referent concepts – this is, principally, the way in which value has been considered in subsequent structuralist anthropology and cultural theory (Sahlins (1985) and Barthes (1972), for example). The need for pluralist conceptualisations of value has been highlighted recently by Skeggs (2014): 'If we can only see from within the blinkers of capital's logic we will never understand or recognize the values that live beyond value. Our own analysis will trap us into that which we are expected to reveal. We therefore, as sociologists, have a duty to look beyond and search for the gaps, the un-captured and better ways of being and doing' (Skeggs, 2014: 16): it is in this spirit that this thesis applies a pluralist reading of value.

7.2 Use-value

So far, this thesis has addressed use-value only briefly, and it has done so purely in conceptual terms by situating use-value in relation to the works of Marx, Mauss, and Baudrillard. For the purpose of analysis, however, thinking about use-value proceeds from a more pragmatic position. What is meant by use-value is a particular logic of meaning whereby the meaning of an action is understood in terms of its instrumentality, its functionality, and its utility. Considering acts of support and assistance in this way is common; however, it is important to identify whether or not such a logic is actually relevant to the experiences of participants in this study in terms of living with illness.²⁷ And this is indeed the case. Where participants discussed their experiences of support and assistance, the most immediately recognisable logic of meaning was that of utility. Bill, for example, spoke about the difficulties he encountered as a result of his OA, and in doing so, referenced the supportive actions of his family:

My right shoulder ...I've had a rotational cuff operation in the shoulder, which made a hell of an improvement, because it got so bad, you know, I couldn't... I had to be helped to put a jacket on, you know, this motion [simulates arm movement]. I mean even that was agony. So you know somebody would put the sleeve in or, you know, I did it with great difficulty myself.

Bill, 1st Interview

In the above quotation, Bill describes the supportive actions of others; Bill does this within a mini-narrative that is defined by a task – putting his jacket on. Bill identifies the consequences of his illness as making this task difficult; prior to an operation, Bill had limited range of movement in his shoulder, and he experienced very significant pain when

²⁷ Use-value is common (albeit tacitly) in existing analyses and interpretations of social support and assistance. As has been identified throughout this thesis, approaches which address supportive practices in terms of their instrumental purpose and/or outcomes may be said to privilege utilitarian or instrumental reasoning (Van der Gaag and Snijders, 2005, 2008; Webber and Huxley, 2007, for example).

completing activities such as getting dressed. In this instance, the primary meaning of the supportive act is the accomplishment of the task at hand with less pain and discomfort. In this sense, the actions of others are readily discernable in instrumental and utilitarian terms.

Similar descriptions of support were apparent across all participants' interviews. Most common were examples whereby friends and family provided incidental support and assistance. Pamela's example is representative of how many participants spoke about support:

When we had the conservatory built I had to get rid of one of the borders... and so Cath [female neighbour] came over with her mother who's from XX [Town], her mother Elaine was staying with her so I've got to know her as well so they came over and helped me dig up my borders and pot things up.

Pamela, 1st Interview

The above quotation is taken from a wider discussion in which Pamela detailed her desire to continue gardening despite experiencing pain, fatigue, and limited mobility (through OA). In this example – as in the above example provided by Bill – the role of other people is presented as part of a task-oriented mini-narrative. In this instance, the task in question involves a degree of physical exertion which Pamela is unable to accomplish without assistance. Due to the fact that this mini-narrative is task-oriented, it is unsurprising that the role of other people should be presented in terms of their useful function – 'they came over and helped me dig up my borders'. Given that Pamela identified the act of gardening as a valued activity, it would be reasonable to assume that receiving support in this way might also be experienced as leisurely, sociable, and self-actualising. However, in the above quotation – framed as it is within a task-oriented narrative – we see the principle meaning of this act as its utility.

The theme of utility was common to many participants' discussions of social resources; however, utility was not interpreted in a universal way. Rather, participants considered utility in relative terms, and in a way which highlighted the connection between illness, individual needs, and the utility of others' actions. Theo and Anne provide a clear illustration of this point. At the time of his second interview, Theo required little or no assistance in terms of physical support. However, due to a number of 'mild' strokes, Theo continued to live with cognitive challenges. As a result, when talking about the forms of support Theo required, Anne identified support in terms of the completion of tasks which involved cognitive abilities – in this example, attending medical appointments.

Anne: *...he's had two strokes he tends to forget. So I go in with him.*

Theo: *Only on the dates and stuff.*

Anne: *And then the doctor will say ... He'll [Theo] say, 'I don't know. It was just on the calendar I've got to come to see you.' So, you know so it's that sort of thing, isn't it. Yeah. So I go in with him, but if I was to go and see the doctor I would just go in by myself.*

Int: *You say... you're [Theo] looking forward, as you said, to that independence, but you still want help - not help, but a bit of support when you go to the doctors?*

Theo: *Yeah, yeah. That's it, yeah. Because I get flummoxed.*

Theo and Anne, Theo's 2nd Interview

Theo's illnesses do not affect his ability to complete everyday physical activities (as in the above examples of Bill and Pamela). Instead, Theo's illnesses present particular challenges which mean that he requires support in completing tasks involving memory or calculation. In the above example, Theo is supported in accomplishing one such task. This form of support is identified by Theo as necessary and useful: 'Because I get

flummoxed'. The utility of this form of support is relative to Theo's illness and concomitant needs. The relative nature of utility is emphasised in Anne's statement that 'if I was to go and see the doctor I would just go in by myself'. This example illustrates that the meaning of utility is particular to individual cases; whilst utility may not be entirely relative, understanding how people appraise the utility of an action requires that we consider their particular illnesses, needs, and their ability to complete desired tasks independently of others.

For some participants, considerations of utility were apparent when deciding who to approach for support and assistance (support seeking). This was more often the case where participants described particular supportive needs, or complex supportive acts.

Some participants described circumstances whereby the specificity of their needs resulted in 'useful' support being difficult to attain: as the complexity of support increased, fewer family and friends possessed the qualities or abilities necessary to support in a useful way. In these circumstances, some participants actively evaluated whether or not somebody would be able to provide support in a useful way. This is apparent in James' experience of support during OA. During this experience, James needed emotional support and somebody to talk to about the physical and existential challenges posed by OA. I asked James whether there were particular people within his social network that he was able to rely upon for this form of support:

I've got a mate of 70, he's as fit... no arthritis, nothing. He's only just started losing a bit of hair! It's not even white, it's still jet black, and when you... when I go out walking with him you know and he's bloody striding ahead up these hills I think 'you jammy bastard!' [Laughs]. So obviously he wouldn't know what you were talking about. I think he... you know, people have to go... for them to be any use they've got to have had a similar experience so to... which I suppose is logical. Until you can usefully share an experience you've got to have actually had it.

James, 1st Interview

James reflects upon his friend's ability to 'usefully share' the experience of illness and in doing so, James evaluates the capacity of his friend to show empathy and to talk knowledgably about illness. James states that because this friend has not experienced OA, he lacks the qualities needed to provide this form of support. James phrases this appraisal in terms of utility: 'for them to be any use they've got to have had a similar experience'. James' appraisal as to the utility of his friend informs his attitude towards seeking support: 'he wouldn't know what you were talking about'. This example emphasises further that utility is a distinct line of meaning, and one which shapes decision-making during illness. Furthermore, James' example highlights that more complex and non-physical forms of support (emotional support, for example) are also interpreted in terms of the accomplishment of a supportive action. It is within this task-oriented framework – the amelioration of emotional, psychological and existential concerns – that James considers whether or not his friend will be 'any use'.

The theme of utility was common to all participants' discussions of social resources. Examples of supportive acts were referenced widely in terms of their place in the accomplishment of a desired task or activity. Accordingly, social resources were conceived within a framework of instrumental action and interpreted as meaningful according to a logic of utility. The above examples indicate the relativity of utility – as something linked to an individual's particular illness, their capabilities, and their desired activities. It has also been suggested that the evaluation of utility plays a role in informing who to approach for support. In summary, whilst this thesis argues for an understanding of supportive acts as meaningful in multi-faceted ways, the above examples underscore the fact that utility remains an important and enduring aspect of meaning.

7.3 Semiotic-value

As has been outlined within Chapter Six (Theoretical review), a semiotic approach is one which seeks to understand the significance of gestures, objects, and actions within a given culture. As such, this form of meaning is distinct from other values which have their seat in the individual (an affective or psychological response) or in particular social relationships. Semiotic-value is drawn from collectively recognised or culturally defined meanings. This section incorporates Mauss' insight into the cultural significance of gift exchange, and seeks to identify the signified meaning – the semiotic-value – of particular social resources

As an illustration of semiotic-value, we might consider first the example provided by David. During his first interview, David identified a friend (Eric) he considered to be particularly supportive; David gave several examples of the ways in which his friend supported him during illness. However, throughout the interview (as was the case in most interviews) I was keen to understand whether there were any forms of support David felt unable to ask for:

Int: *Is there anything you feel you, you couldn't ask for?*

David: *His missus. [laughs] She's bloody gorgeous. No, no, I could ask for anything. Anything at all. If I said to Eric, 'Can you lend me 500 quid?' he'd go and get me 500 quid, you know. No problem, like.*

David, 2nd Interview

In the above example, David states that he feels able to ask for 'Anything at all', and supports this statement with a hypothetical example involving money. The use of money in this instance is not coincidental; money functions as a rhetorical device, as something which might otherwise be considered unacceptable. To understand this meaning, we must consider the meaning of money not simply in economic terms, but in terms its cultural significance. In David's example, the meaning of money might be interpreted as

drawing upon a culturally recognised system of normative wage/labour relationships. Within this example, no labour is exchanged between David and his friend, and so the exchange of money appears to be in some sense remarkable. David, whether tacitly or not, recognises this meaning and plays upon it in demonstrating that this relationship transcends the conventions of economic exchange. Instead, this relationship involves qualities which enable David to take money without providing anything in return (illustrating these qualities being the purpose of his statement). Alternatively, we might point to the fact that David chooses a particularly large sum of money to evidence his point. The figure of £500 functions in a way that £50 would not. The large sum of money plays upon a collective recognition as to the economic value of £500, and serves to illustrate that a high degree of trust exists between both men. Whether or not we choose to accept either of these particular readings, it is a point of fact that David's statement would not function were it not for the cultural significance of money. David invites us to recognise this significance, and in doing so, demonstrates that he is able to ask 'Anything at all' of his friend.

Among other participants' interviews, the cultural significance of social resources was evident where supportive acts were presented as gendered actions. Mo, for example, described the role of certain people in within her social network:

My son-in-law's next door as well. He's a plumber so any – and he's quite handy so any sort of big jobs or anything then he's, he's sort of pretty good with that. And my daughter's sort of quite good, you know, if we have a bit of a flare up and... you know, I say to her 'Oh, do me a favour' and she'll sort of, you know, Hoover up and polish and ... do the bits and bobs like that.

Mo, 1st Interview

In the above quotation, Mo makes a distinction between 'big jobs' and 'bits and bobs'. Mo identifies 'big jobs' with her son-in-law, and 'bits and bobs' with her daughter; in doing so,

Mo provides a gendered account of support. Mo's choice of phrasing suggests that she considers 'big jobs' to be more significant, demanding or important than 'bits and bobs'.²⁸ We might easily interpret this as Mo according male labour with greater importance than female labour. Elsewhere, Rose also identified certain supportive acts with female family members:

Jenny, who he lives with, she comes on a Saturday afternoon and cleans all through and does all through for me. And then Alice will come during the week and she'll run the Hoover round. But I can't do a lot of things now, which annoys me

Rose, 1st Interview

In considering the meaning of these supportive acts, we might think primarily of utility; Rose emphasises utility in stating that she is unable to complete these actions without the help of others. However, Rose's account also makes plain the association between domestic labour and female family members. In this sense, the meaning of these supportive acts must be understood both in terms of utility and also, in cultural terms, as gendered actions.

A more lucid illustration of social resources as gendered actions was provided by Bill and Cath. The following interview excerpt is taken from a discussion about the role of neighbours in providing support:

Bill: *There's a lad just across the way, he's a mechanic and, and he goes to anybody, you know, he'll, he helps anybody, doesn't he?*

Cath: *Who, Chris?*

Bill: *Chris.*

²⁸ I understood 'bits and bobs' to mean domestic labour within the home.

Cath: *Oh, yes, he's a car mechanic...*

Bill: *Chris and David...*

Cath: *...and then the fellow next...and then David, the fellow next door...*

Bill: *...comes if you've any problems with the television.*

Cath: *...say if you want anything electrical doing or fix-it jobs, he just comes across.*

Bill and Cath, Bill's 1st Interview

Bill and Cath identify 'fix-it jobs' (tasks involving skill and technical expertise) as the preserve of male neighbours. As they continued this discussion, Bill and Cath proceeded to identify the forms of support provided by their granddaughter (Ellen):

Bill: *Granddaughter, Ellen, she does our, comes and...*

Cath: *She comes and helps and does a little bit for me, you know, when she can...*

Bill: *Cleaning.*

Cath: *...because she's working and she's going to...*

Bill: *She's going in for nursing.*

Cath: *...college and for nursing... but she does come and give me a bit of a hand.*

Bill and Cath, Bill's 1st Interview

Here again, domestic labour is associated with female family members. Bill and Cath also make a connection between this form of support and their granddaughter's desire to become a nurse. In this instance I felt that Bill and Cath were inferring that their granddaughter has an aptitude for this form of work.

The above examples are representative of many other cases wherein acts of support and assistance were discussed in terms of normative gender roles. Accordingly, domestic work was associated widely with female labour, while manual, technical and mechanical tasks were associated with male labour. It is important to recognise that there is nothing 'natural' about this division of labour, nor is it simply a reflection of an empirical reality: gendered divisions are constituted by reality, but they are also constitutive of it. For the above participants, the acts of support and assistance described may have been understood primarily in terms of their utility. However, in seeking to understand the meaning of social resources in a more holistic way, we must also recognise the culturally constituted meaning of these actions as gendered activities.

A further instance of semiotic-value was apparent as participants spoke about the meaning of intimate and personal care. Although this form of support was not widely experienced by participants in this study (only two participants reported having received this form of support), many identified personal care as a particularly meaningful activity. David, for example, spoke at length about his daughter's willingness to assist him in whatever way he might need (including domestic work, the provision of transport, and even co-habitation). However, when asked whether he would ever feel uncomfortable asking for support, David replied:

Oh, if I get ... if somebody had to come and help me shower, I wouldn't be happy with her doing it, you know.

David, 2nd Interview

David was quick to identify personal care as something he considered problematic. Despite the strength of their relationship, David considers personal care to be inappropriate or unacceptable. Elsewhere, Isla raised similar concerns when talking about her best friend and neighbour. Isla identified this friend as the most important person in her life, she reflected: 'It's amazing really what she does'. However, as with David

(above) Isla was adamant that some forms of support were not appropriate within this relationship:

Int: *Is there anything you'd be embarrassed to ask for or...?*

Isla: *I don't think she could do anything personal. I don't think she could do anything like that.*

Int: *You wouldn't want her to?*

Isla: *No, oh no. I think that would be a problem from that angle. But she'll do anything else, but I think if I needed help that way I don't think she could do that.*

Isla, 1st Interview

Isla's comments reveal the powerfully emotive meaning of personal care: even within her closest supportive relationship, Isla considers this form of support to be embarrassing and unacceptable.

The above examples are representative of several participants' comments regarding personal care. As in the (above) consideration of gender, we must be mindful against dismissing such responses as 'natural'. Rather, the meaning of personal care should be recognised as, in part, culturally constituted. Accordingly, the meaning of personal care may be understood by reference to cultural norms concerning the body, bodily control, and privacy. One approach to the issues of bodily control and shame has been to refer to Elias' theory of the 'civilizing process' whereby the body becomes socialised, rationalised, and individualised (Elias, 2000). From such a perspective, the body does not have a neutral relationship with culture or society. Rather, the meaning and practices of bodily functions come to be shaped by social, cultural and political forces (Shilling, 1993). Under such conditions, control over the body and self-discipline become paramount, and the 'correct' functioning of the body is tied to individual and collective representations of self

and identity (Gilleard and Higgs, 2013). Accordingly, what it means to be a 'dignified individual' concerns control over the body and ensuring the privacy of intimate moments. In the examples of David and Isla, we might interpret personal care as significant in these terms; personal care in this sense signifies a personal failure or the transgression of cultural norms, invoking shame and embarrassment.

A further semiotic-value was apparent as participants identified support and assistance as signifying dependence and independence. Ian is exemplary of many participants in this regard. When asked about the role of other people in his life, Ian responded by stressing his own capabilities:

'In general things, they don't have to do anything for me, you know? And, in fact, I feel better doing it myself, you know... If I want to get on with something, you know, I do it.'

Ian, 2nd Interview

Ian expresses a sense of fulfilment at being able to act independently and without the support of others; in this sense, Ian is typical of most participants in representing independence as a positive characteristic. However, accompanying such positive representations of independence were negative attitudes towards the receipt of care. Isla, for example, spoke about the prospect of asking for support:

I'm the sort of person that doesn't do that kind of thing [ask for support]. Too independent I suppose.

Isla, 2nd Interview

Isla, like many participants, considered independence to be a virtuous characteristic. In the above quotation, Isla identifies herself positively as 'the sort of person who doesn't do that kind of thing'. Although implicit, I gained a sense throughout her interviews that Isla

considered support-seeking to be a sign of personal failure. In a similar fashion, Mary also distinguished herself as an independent person:

I wouldn't like to be a person who was always on the phone, "I can't do this and I can't do that", I've never done that.

Mary, 1st Interview

Mary presents herself positively as an independent person and contrasts herself to another hypothetical persona – the 'person who was always on the phone'. Mary invokes the voice of this other person in saying 'I can't do this and I can't do that'. The tone of Mary's response suggested that to ask for support may be seen as being demanding or burdensome. Further, there was also a sense that having to ask for support may be avoided through working hard to maintain independence. In the examples of David, Isla and Mary we gain insight into the cultural meaning of independence and dependency. Across participants' accounts, independence was presented as virtuous whilst receiving support was associated with dependency and seen as an aberrant act. These themes did not adhere to any particular type of support; rather the meaning of independence and dependence were presented as undesirable in most acts of support.²⁹

In summarising the logic of semiotic-value, it is important to note that some forms of meaning are irreducible to individual psychology, or to co-constructed meanings particular to certain social relationships. In this regard, social resources have a semiotic-value where they signify meaning within a cultural system. The above examples illustrate how this form of meaning might coalesce with other value forms; money, for example, has both a cultural and an economic value. Participants' discussions of social resources revealed a number of semiotic-values. Specifically: social resources as gendered activities, intimate care as a personal failure and the cause of shame and embarrassment, and the meaning

²⁹ The themes of independence and dependence will be addressed further in the following chapter.

of dependence as a form of aberrant act. These meanings were not immutable and were discussed with some diversity among participants. In general, however, the cultural significance of particular acts of support is an important consideration in comprehending social resources as meaningful social actions.

7.4 Symbolic-value

As discussed in the previous chapter, in symbolic exchange (as opposed to commodity exchange), the object or action exchanged is experienced as inalienable. This inalienability results in the exchange deriving meaning from the identity of the giver and the relationship within which exchange takes place. In supportive acts we can think of symbolic-value in similar terms. Symbolic-value does not pertain to any innate quality of the supportive act, nor does it refer directly to its cultural significance. Rather, symbolic-value recognises that social resources may, like gifts, be experienced as inalienable – the giver gives-of-themselves, and the meaning of this action is shaped by the relationship within which it is exchanged.

As an illustration of symbolic-value in practice, we might consider David's experience of caring for others. David spoke about his experience of caring for a long-term friend (David's friend lived alone and required care as a result of blindness and Alzheimer's disease). David supported his friend by maintaining her home and garden, by preparing meals and ensuring her safety generally. These forms of support might typically be understood in terms of their utility; however, as David spoke about this experience, it became clear that these supportive acts had assumed another meaning:

David: *She started with Alzheimer's, so then I was having to do her shopping and pay her bills and one thing and another, not that I minded, but you're tied. You know, if you go on holiday you've got to arrange for somebody to go and do the shopping for her. You've got to make sure her dinners are going to be there when, when they should be and you're doing a lot of running*

about for nothing, really. So, if anybody wants any help I'll come and, I'll give them the best I can, but it won't be on a long-term basis.

Int: *Is that because of that experience you've had then?*

David: *Yeah, it makes life very difficult for you, especially when they're no relation to you, you know. If my daughter was in a situation where she wanted help, then that's a different ballgame.*

David, 2nd Interview

As a care giver, David was required to devote an increasing amount of time and energy towards the care and safety of his friend. In the above quotation, David reflects upon this by stating 'not that I minded, but you're tied'. In this sense, David emphasises the degree to which he felt responsible for his friend, and suggests that this responsibility began to impinge upon his life. The demands of this care-giving role became such that David felt his own freedom curtailed. David suggests that were a similar situation to occur again, he would not allow himself to become committed on a 'long-term basis'. In concluding his comments, however, David informs us that 'If my daughter was in a situation where she wanted help, then that's a different ballgame'.

The meaning of support in this example may not be understood by recourse to the concepts of use-value or semiotic-value alone: what is required is the concept of symbolic-value. Recalling parallels with gift exchange, symbolic-value refers to the meaning of the exchanged object in terms of the giver, and the relationship between giver and receiver. In this example, David expresses the sense by which he was required to give-of-himself; he commits to the responsibilities of care and relinquishes personal freedom. Further, symbolic-value requires us to consider this meaning as relative to particular relationships.³⁰ This is apparent in David's assertion that should the same

³⁰ Recalling Baudrillard's analysis of the wedding ring: 'This is a unique object, symbol of the relationship between the couple. One would neither think of changing it (barring

situation occur involving his daughter, he would be happier to provide such care and support. Symbolic-value in this example captures the sense by which Ian gives-of-himself, and also the relativity of this meaning to particular social relationships.

Elsewhere, participants evoked symbolic-value in conveying the significance of supportive actions which might otherwise be considered somewhat mundane. Judith, for example, spoke about the transport provided by a friend (Liz). Across all participants, transport was the most commonly cited form of social resource received, and was usually discussed in terms of utility. For Judith, however, this supportive act was experienced not simply as useful, but as symbolically valuable:

When my husband was working, Liz was always there for me although she lives out at XX [15 miles away] someone is there to have... when I first left work I was going to the doctor's every week, he made me go every week, I had an appointment every week so if David [husband] wasn't here... I've seen that woman [friend] come at 8 o'clock in the morning from XX [15 miles away] in her nighty with a coat over it just to take me to the doctor's and she's sat in the car park while I've gone in, brought me home then gone back home and got a shower or whatever she does then, you know, because she's had to come out at half past seven you see because of the traffic. I couldn't wish for a better friend.

Judith, 1st Interview

In the above excerpt, Judith seeks to demonstrate the significance of this supportive act, and she does so in a manner which highlights the ways that her friend has given an inalienable part of herself. Judith's commentary is laden with references to the sacrifice

mishap) nor of wearing several'(Baudrillard, 1981: 66). The meaning of the ring is particular to the relationship within which it is exchanged; similarly, the meaning of supportive acts are particular to the relationships within which they are given and received.

and difficulties her friend has experienced in providing her with this support: her friend was required to travel some distance (15 miles) to support her; there are multiple references to 'every week' (conveying the regular and long-term nature of support); the imagery of her friend waiting in a car-park whilst still wearing her night clothes; and the wider disruption of her friend's daily routine. In providing us with this commentary, Judith emphasises the meaning of this resource in terms of what her friend has given-of-herself: her time, energy, and freedom. For Judith, the provision of transport is neither mundane nor simply utilitarian; to understand why this is the case, we require an appreciation of the symbolic-value of this supportive act.

Symbolic-value was also apparent where particular social relationships enabled otherwise problematic forms of support to be exchanged – this was most apparent in relation to personal care. As has already been identified, personal care was cited widely in negative terms as something which could not be exchanged between family and friends. However, where participants spoke of personal care being acceptable, it was often specific social relationships which made this possible. One example was provided by Judith:

I mean I've got my husband here, like he has to help me, I can't get in the bath any more... So he has to help me you see. I can step, he'll help me to get over the bath because it is painful to do that and he's put me a thing on the wall to hang on to and he has to help, he has to wash me down at the back because I can't reach me back, you know. He helps me like that then he helps me out. If I need my hair washing...I have my hair done once a week but if I need it washing in between he'll do it for me.

Judith, 1st Interview

In the above quotation, Judith describes intimate care in neutral terms; she does not consider such care to be in any way embarrassing or shameful. During her interview, I interpreted Judith's relationship with her husband as playing an important role in this supportive act, and the fact that this form of care was acceptable was attributable, largely,

to the relationship within which it was exchanged. Elsewhere, Mo also identified the importance of particular social relationships in defining the meaning of personal care:

I'd probably feel comfortable with, with my daughter, because I was there at both – she's got two children, I was there at the births and things. So there's... it's a different sort of bond that you have with your daughters. So any sort of personal things I'd, you know, if it ever came to that, it wouldn't bother me my daughter sort of helping in that way. It probably would with my son ... I think he'd ... he'd be more than willing to do it, but I wouldn't like him to.

Mo, 1st Interview

Mo identifies the meaning of personal care as relative to particular relationships; this form of care would be acceptable when provided by her daughter, but unacceptable when provided by her son. Mo emphasises particular qualities in her relationship with her daughter, stating 'it's a different sort of bond that you have with your daughters'. Clearly, this dynamic may be associated with the gendered nature of familial relationships. However, Mo also emphasises the fact that she has shared in the experience of her daughter giving birth and suggests that sharing such intimate experiences has ameliorated any anxiety and stigma which might usually be attached to intimate care. In this sense, the symbolic-value conferred by this relationship moderates the meaning of intimate care away from a stigmatised act, rather it comes to be regarded as an act of intimate co-operation which is acceptable to Mo.

For some participants, however, symbolic-value was experienced as problematic and meant that even relatively minor acts of support were deemed inappropriate. Mo, for example, spoke about the prospect of asking her best-friend for support:

If I asked... she'd help, you know. But, she's got a family as well that she's... you know, very involved in. So, I've not had to ask her for any help... because I've got, you know, my own family will do it for me.

Mo, 1st Interview

When talking about this friendship, Mo struggled to define the extent to which the relationship would sustain supportive acts. In the above quotation, Mo equivocates in stating that support would be available, and yet she would be reluctant to ask for it. To understand why this is the case requires us to consider the meaning of support as indissoluble from Mo's interpretation of this friendship. Mo feels that to receive support within this relationship would be to ask too much of her friend. Mo illustrates this by stating that 'she's got a family as well that she's... you know, very involved'. Mo affirms the relative meaning of support by stating that 'my own family will do it for me', demonstrating that the same supportive acts would be interpreted differently when provided by a member of her own family.

In summary, there is an inalienable quality to non-economic exchange which sees meaning linked to the identities and to the relationship between those individuals involved in exchange. This form of meaning is conceptualised as symbolic-value. In the above examples, it has been demonstrated that without the alienating force of money, social resources are often experienced as inalienable from the person giving support. This is evident in the ways that a giver of support is understood to be giving-of-themselves. Some participants spoke about this aspect of meaning in a problematic fashion, as something which made social resources difficult to accept from friends and family. However, it has also been demonstrated that symbolic-value has the potential to mitigate the stigmatised meaning of certain forms of support, thus making them less problematic and more acceptable.

7.5 Exchange-value

Participants spoke about supportive exchanges, overwhelmingly, as occurring outside of commodity exchange. Despite this, several participants also identified supportive actions within formal economic relationships. Further, it was also apparent that for some, the logic

of economic exchange continued to shape the meaning of supportive symbolic exchanges (non-commodity exchanges). In recognition of these issues, this section details the contribution of exchange-value in defining the meaning of social resources.

For some participants, the meaning of supportive acts was informed by knowledge of the equivalent cost of support in economic terms. Judith, for example, discussed her feelings about providing support to her friend:

I said, "Liz, you're not coming from XX [town]... you're not having a taxi, I'll come for you", because I used to have a taxi you see... they're too much £5 there and £5 back, you know.

Judith, 1st Interview

Judith presents herself as taking control and demanding that her friend accept the offer of transport. Judith is motivated by her knowledge as to the equivalent cost of this support from an economic provider – ‘they’re too much £5 there and £5 back’. Judith feels this price to be too high, and that she is able to provide the same support at minimal cost to herself. As a result, Judith implores her friend to accept support rather than paying for a taxi. This example illustrates clearly that whilst social resources, by their nature, are exchanged within social relations (rather than economic relations), there is the potential for economic logic to endure and shape meaning. Judith is aware of the exchange-value of transport, and this knowledge contributes to her understanding of transport as a meaningful social resource.

The most common instances of exchange-value came as participants struggled with the meaning of symbolic-value. In these cases, participants worried about asking ‘too much’ of their friends and family, and paying for support was widely identified as preferable. Pamela, for example, spoke about her decision to pay for domestic support rather than relying upon her family:

I mean it's unrealistic to expect... you know Louisa is the nearest really and then I've got a brother in XX [15 miles away] and, my cousins are in XX [20 miles away] and my nieces are in XX [20 miles away]... and my brother and his wife and their two sons were in XX [100 miles away].... So the physical part of it... yeah we can afford to have some help.

Pamela, 2nd Interview

Pamela believes that it is 'unrealistic to expect' her family to support her because they live 15-20 miles away: to 'expect' such support would be to ask too much of them. Instead, Pamela employs a professional cleaner to provide this support. In paying for domestic support, Pamela avoids asking her friends and family and this is experienced as less problematic. Elsewhere, David also worried about asking too much of his friends, and identified paying for support as less complicated:

It'd be easier just to pay them. I know... I know that they [friends] would do it, but then again it's committing them, and they've got their lives to live as well as me, you know, so it wouldn't be right to expect them to come round here two or three times a week to help me out. Occasionally, no problem, but it, it wouldn't be right to expect them to, to do anything on a long term. Just pay them.

David, 2nd Interview

David states that his friends are willing to support him; however, he does not feel comfortable with the prospect of receiving support over an extended period of time: 'it's committing them, and they've got their lives to live'. As a result, David proposes that paying for professional care would be 'easier'. In paying for support, the meaning of symbolic-value is no longer predominant, and support becomes less problematic and easier to accept.³¹

³¹ The reasons as to why accepting support and assistance might be difficult and problematic will be addressed in the following chapter. At this point, for the purpose of

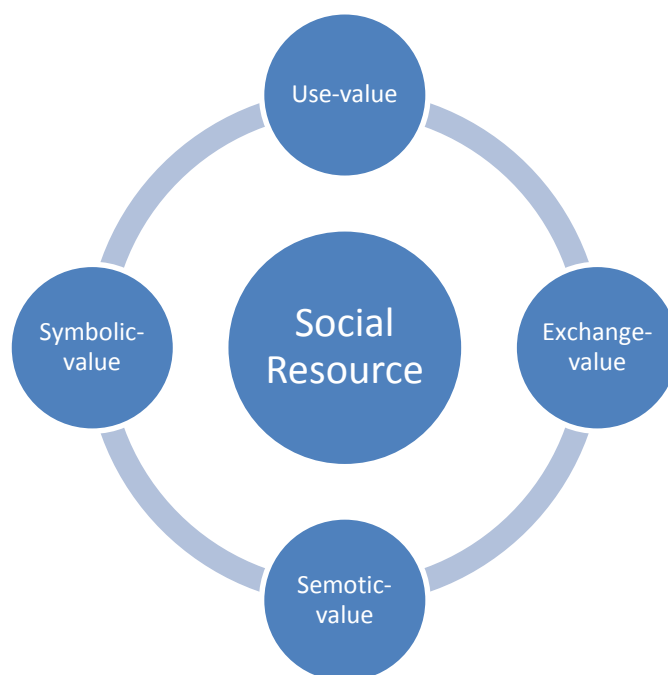
The above examples highlight that exchange-value continues to inform the meaning of supportive acts, particularly where support is exchanged as a commodity. For some participants, the interjection of money altered the meaning of exchange. Most notable was the effect of money in moderating the symbolic-value of supportive acts. In considering why this occurred, one plausible explanation is to recognise the power of money as an alienating force. As has been argued (above), a supportive act exchanged within symbolic exchange is experienced as inalienable. However, an economic transaction allows for the same supportive act to become alienated from the giver in exchange for immediate remuneration. As a result, where social resources were discussed as commodities, they were no longer referenced in terms of their symbolic-value. Where this occurred, participants experienced economic exchange as easier or less problematic, and several participants identified economic providers as preferable to receiving support and assistance from friends and family.

7.6 Social resource exchange: an interpretive economy of meaning

This chapter has identified four distinct logics of meaning: use-value, semiotic-value, symbolic-value, and exchange-value. For the purpose of clarity, it has been necessary to introduce each of these aspects in an individuated way as independently occurring logics of meaning. However, in practice, participants did not always discuss meaning in such neat or disambiguated terms. Instead, these logics of meaning were represented by participants as coalescing and intersecting in what might be termed an *interpretive economy of meaning* (see Figure 1).

clarity, this chapter addresses the dynamics of this exchange in terms of meaning and value alone.

Figure 2: Interpretive Economy of Meaning



The above model is useful for our understanding of social resources, particularly in cases where exchange appears complex and meaning is seemingly ambiguous. The following section illustrates, using just two examples, the way that these various forms of meaning are experienced in social practice.

As a preliminary example, we might consider David's second interview. During this interview David spoke at length about what he considered to be a meaningful difference between instances of one-off support, and support provided over an extended period of time. David stated that he would not feel comfortable asking his friends for long-term support, and he then proceeded to discuss one example in detail:

Int: *Is it easier to ask for the help on a one off basis then?*

David: *Yeah, I wouldn't expect anybody to come and... look after me full time you know. I've, I've got a new hedge cutter in the garage. I think I've used it twice, and I said to Jim (male neighbour) the other day, next door, he does a bit of gardening... I said, 'When you cut your hedge,' I said, 'come and cut my side.' All right, it'll cost me a tenner, but he'll be out there while I'm bloody thinking about it.*

Int: *So you, you give him a tenner did you?*

David: *I give him a tenner when he comes round and cuts the grass, cuts the hedge for me.*

Int: *Does that make it... does that make it different again, if you give, if you just give someone a tenner?*

David: *He's the only, the, the only one I do give money to. I don't give it to anybody else.*

Int: *Is it... I mean this isn't easy to explain, maybe, but why do you give him money?*

David: *Because he does it for a living.*

Int: *Ah I see...*

David: *He's, he's out nearly every day gardening somewhere, it's basically a job. So you can't expect him to come and cut it for nothing. But my mate up, down the road there, he'd come and cut it me for nothing, but he's got his hands full with his brother. He's looked after him for the past 10 years, you know, and I wouldn't expect him to come and do it.*

Int: *Right...*

David: *But, as I say, Jim (male neighbour) does it for a living... so you can't expect him to cut mine, mine for nothing, and then go and charge the bloke next door for cutting his, can you?*

David, 2nd Interview

In the above example, several distinct lines of meaning may be discerned, each of which must be considered if we are to understand this example in its entirety. Firstly, we might consider the immediate meaning of this social resource in terms of its utility relative to Ian's needs and capabilities. Elsewhere in his interview, David stated that he took enjoyment in keeping a well-maintained garden; however, as a result of OA, David is no longer able to undertake the amount of physical activity he once did. Consequently, David is unable to keep up with gardening alone and needs supporting in this way. From this perspective, it is easy to recognise the support provided by David's neighbour in instrumental terms as necessary to the accomplishment of a desired activity – its use-value is clear.

Beyond this immediate utilitarian meaning, any interpretation as to a semiotic-value might be inappropriate – after all, what cultural significance might hedge-cutting possibly assume? We might reasonably question whether this form of support has a gendered aspect to it; it is possible that David considers this form of support to be 'male work', and it is interesting to note that David did not mention his daughter or a female neighbour in this example. However, given the data available in this quotation, any further assumptions would be somewhat tenuous.

The most striking feature of this exchange is, therefore, David's decision to pay his neighbour for support. That David should pay his neighbour may seem incongruous given the apparently informal nature of their relationship and this is emphasised by David's confirmation that this neighbour is the only person he pays for support. However, when asked why he pays this neighbour, David states clearly that this is because his neighbour

is a gardener by profession. Recalling Mauss' observation of gift exchange whereby 'objects are never completely separated from the men who exchange them', this may be recognised as a form of symbolic-value. David pays his neighbour because this specific form of support (gardening) when given by this specific individual (a gardener) has a particular inalienable quality. To receive this form of supportive act without payment would be to take too much of this person, it would be asking them to give of themselves in an inappropriate fashion. David confirms this supposition in stating that he would happily receive this form of support without payment from another friend. However, David then states this is not possible due to his friend's existing care responsibilities; asking this friend for support would be to ask too much of him (here again, meaning in terms of symbolic-value). In paying for support and introducing exchange-value, the support of Ian's neighbour is transformed into a commodity. Once commodified, the meaning of this supportive exchange is altered fundamentally: the supportive act becomes alienated from his neighbour, symbolic-value is diminished and the supportive act is no longer experienced in terms of the neighbour giving-of-himself. Rather, David's neighbour provides a service which is bought according to the norms of economic exchange. With the ascendancy of exchange-value, other forms of meaning recede, and David feels comfortable accepting support.

As a further illustration of the interpretive economy of meaning, Isla provides an interesting example. As was outlined in Chapter Five, Isla has no local family (her son lives approximately 150 miles away), yet she is very well connected in her immediate neighbourhood as well as the wider community. When talking about support, Isla identified a small circle of friends who provide her with regular support and assistance. In the following quote, Isla began to detail the supportive roles people by members of this group:

Int: *so does it feel like you've got a circle of friends?*

Isla: *Oh yes, yes. Indeed yes, yes. Different people do different things. Like I get... the people who take me to church and... I try not to... you see, I look at it this way: I get this money to pay for these things and so I have a taxi. I have a taxi – I have a regular booking every Wednesday with XX [company]. I take my scooter on the taxi... I go with my neighbour next door and we do different things. Go to the supermarket and we do – nothing exciting, but we go out and we have lunch out. But if I needed to go again somewhere I would have the taxi, you see.*

Int: *Okay, you'd rather use the...*

Isla: *Oh yes, yes. Because you see, another thing, you see... I mean I have a wheelchair as well, but the people that deal with me are in my age – not necessarily particularly in my age group, but round and about my age group, and are not really able now to lift wheelchairs and things into the boot, so that is a problem.*

Int: *So thinking about the taxi example then, there's a physical reason there why you...*

Isla: *Yes, yeah.*

Int: *And does it feel comfortable paying for it?*

Isla: *Oh yes. I prefer it, yes, yes. They're very, very good, the taxi men.*

Isla, 1st Interview

Isla's health and mobility are such that she is only able to walk a few yards without assistance. Due to her limited mobility, Isla spends the majority of her time confined to the downstairs rooms of her home. As a result, the occasional visits she makes – to the local church, shopping, lunches with friends – are paramount to her wellbeing. In this context,

the provision of transport support is essential to Isla's continuing social engagement, the maintenance of relationships, and her participation in valued activities. In this regard, having somebody who will drive her and assist her physically in these activities has a clear instrumental role; Isla would find these activities impossible without support.

However, the meaning of this transport in this example is not limited to utility alone. Isla states that because her friends are of a similar age to her (inferring they share similar challenges in terms of physical activity) they experience difficulty in supporting her (lifting her wheelchair into their cars, for example). Here we might recognise an element of symbolic-value; the provision of transport takes new meaning when Isla's friends have to struggle to support her. Asking friends of a similar age to support her in this way (on a regular basis) is to ask too much of them. Isla recognises this meaning and she is uncomfortable with it: 'so that is a problem'.

As a result, where Isla requires this form of support on a more regular basis, she uses her DLA payments to pay for taxis. Here again, with the introduction of exchange-value, the meaning of transport is altered. Isla states that she prefers to pay for this form of support; I interpreted this to mean that Isla would prefer to pay a professional rather than allowing her friends to struggle in supporting her. With the introduction of exchange-value, this symbolic-value is no longer a defining feature of the exchange and Isla experiences the supportive act as less problematic and easier to accept.

7.7 Discussion

The primary aim of this chapter has been to outline the ways in which various acts of support and assistance are experienced as meaningful. In doing so, this chapter has proposed a pluralist model of value inclusive of distinct logics of meaning. Use-value, economic-value, symbolic-value and semiotic-value have been shown to capture distinct aspects of meaning: utility, economic, relational, and cultural. It has been argued that the experience of social resource exchange involves the coalescing and intersecting of these

logics of meaning. This has been conceptualised and depicted in what has been termed an *interpretive economy of meaning*. What remains to be explored are the ways in which morality underpins practices of social exchange, and it is this issue towards which this thesis now turns.

Chapter Eight: Morality, ethical work and social resources

8.1 Introduction

This chapter elucidates the role of morality in shaping the experience of giving and receiving social resources during illness. The previous chapter (Chapter Seven) identified the ways in which supportive acts are experienced as meaningful; the current chapter builds upon this insight, and locates the meaning of social resource exchange within the context of the formation of an ethical Self.

Chapter Six (Theoretical review) identified the enduring role of morality within social exchange theory. Further, it was demonstrated that in contemporary perspectives – informed by social exchange theory and latterly RCT – morality is conceived in a limited sense according to the principle of reciprocity. The limitations reciprocity have been identified in both substantive and analytic terms. These caveats aside, empirical research – and qualitative research in particular – has demonstrated the continued significance of morality in giving meaning to peoples' experiences of illness (Frank, 1995; Kleinman, 1988; Williams, 1993) as well as, to a lesser degree, shaping the meaning of cooperation during illness (Blaxter and Poland, 2002; Rier, 2007). In the wider sociological and anthropological literature, there is a clear acknowledgement as to the importance of morality in shaping individual dispositions, behaviour, and social action. Shweder (2012), for example, summarises the relevance of morality:

Moral judgements are motivators of action in significant measure because they are affect-laden and produce in people powerful feelings of arousal, distress, pollution, repugnance, guilt, indignation, pride, or shame (Shweder, 2012: 90).

As such, morality must be recognised as an important and enduring feature of the experience of illness, with the potential to shape how supportive practices are enacted and experienced. This chapter assumes this position, and will describe the various moral dilemmas and deliberations encountered by people living with multimorbidity when

drawing upon others for support. In doing so, a number of distinct moral principles will be highlighted. It will be argued that these moral principles play a role in shaping emotions, feelings and actions during the receipt of support. It will then be argued that people in receipt of support engage in 'ethical work': understood to mean the dispositions or actions assumed in order to accomplish the aforementioned moral principles. Finally, this chapter will discuss these issues critically; drawing on Foucault's notion of the production of 'ethical subjects' and C.B Macpherson's concept of 'possessive individualism', this chapter will conclude that the receipt of support is often experienced as a form of social suffering wherein people living with illness struggle to maintain themselves as ethical individuals.³²

8.2 The virtue of independence, receiving as erring

Independence is a complex and multifaceted concept. At its core, however, independence concerns the embodied and inter-subjective relationship between Self and Other. Much extant health literature identifies independence as a defining tenet of 'successful ageing', or as an essential feature of a 'full' and 'productive' life during older age and chronic illness (Alpass et al., 2007; Baltes and Carstensen, 1996; Bowling and Dieppe, 2005; Rozanova, 2010; Martinson and Berridge, 2014). In this respect, independence is represented, largely, in terms of physical independence and its concomitant psychological benefits emanating from feelings of autonomy, control and self-determination. In the first instance, it is difficult to question this rationale: independence surely is salubrious for physical and mental health as well as general wellbeing. Indeed, independence was identified by several participants in this way, as contributing to their self-defined health and wellbeing. For many, however, independence was not only a defining feature of health and wellbeing, but was also presented as a moral object or territory. The following

³² Here the word 'individuals' is not intended to be neutral, rather it emphasises the possessive individualist character of that which participants represented as 'good', morally virtuous or decorous. This issue will be addressed within the discussion section of this chapter.

section takes up this observation, and outlines the ways in which participants represented independence and dependence as moral principles.

As has been noted in the previous chapter, the themes of independence and dependence were identified by several participants when discussing support-seeking. To reiterate, we might consider the perspectives of Isla and Mary, both of whom spoke about the prospect of seeking support:

I'm the sort of person that doesn't do that kind of thing [ask for support]. Too independent I suppose.

Isla, 2nd Interview

I wouldn't like to be a person who was always on the phone, "I can't do this and I can't do that", I've never done that.

Mary, 1st Interview

For both Isla and Mary, independence is a question which speaks to the very foundations of who they are: it is a question of identity. In defining themselves as independent people, Isla and Mary are established as morally authentic subjects; this is achieved in the above excerpts by positioning themselves as counterpoised to a hypothetical Other – the 'dependent person'. Isla states that she is 'the sort of person that doesn't do that kind of thing', whilst Mary affirms that she is not 'a person who was always on the phone'. This observation is important, and illustrates that the meaning of independence is inextricably linked to that of dependency. In discussing independence, both Isla and Mary make tacit statements about dependency. In this regard, identifying themselves as independent serves not only to affiliate with the positive image of independence, but also distinguishes both women from dependence as a morally aberrant status.

The contingent nature of independence is, of course, thrown into sharp relief by illness. Illness imposes itself upon social relationships; previously known friendships and kinships

withstand or break under the weight of illness, and those which endure often develop into supportive relationships. This process, however, is not always an easy one. As Rose described, the love and care afforded by friends and family may also be experienced as a threat to one's moral status as independent. As a result of her OA, Rose requires significant support and assistance on a daily basis. Fortunately, by virtue of her extensive local family network, Rose has no shortage of willing supporters: 'I'm waited on, hand and foot'. However, in describing her everyday experiences of support, Rose also alluded to her misgivings about asking for support. I questioned whether these misgivings were the result of any specific experiences:

I don't really know, they're all pretty good, you know. But I'm a bit independent; I don't like asking. And I think, 'No, I'm not asking you,' and then somebody will come along and say, 'Oh, Nan, do you want so-and-so?', 'Oh, yes, all right'.

Rose, 1st Interview

Like many other participants, Rose describes herself as an independent person and identifies this characteristic as making her feel uncomfortable about support. In the above quotation, Rose states that she avoids asking her family for support; however, when support is unsolicited, Rose feels more comfortable in accepting. This case suggests that there is something particular about the act of requesting support which contributes to Rose's discomfort. In considering why this might be so, it is quite possible that the act of requesting support has a number of negative connotations such as personal failure, or wider cultural representations of neediness, even destitution. This would certainly seem logical given that such meanings are in direct contradiction to Rose's self-proclaimed status as an independent person. Rose manages this situation through her efforts to defer support until it is offered without solicitation, and even then, only accepting with an air of reluctance – 'oh, yes, all right'. For Rose, as for other participants, independence is not just about her own self-sufficiency, but is defined also by her dependence on others.

Where participants spoke about independence in moral terms, it was usually represented as being a 'good' thing out of consideration for other people. Isla explained her feelings towards supportive relationships – in particular that with her son – and revealed the tensions she experienced within this relationship. Isla, like Rose, was not comfortable with the prospect of asking her family for support:

I think it's good for your family if you can be independent. I mean my son will say to me – I mean I remember when he was very busy, when he was working he used to travel all over the world and that, and I tended to wait until he rang me. I would say to him sometimes, if I hadn't heard from him for a bit, "Oh just a minute, I don't recognise your voice." He would say, "Mother, it works both ways, you've got a phone as well". So, you see, I tended to – if I didn't ring him, then I wasn't bothering him.

Isla, 2nd Interview

Isla discusses independence in terms of what it means for other people - 'it's good for your family if you can be independent'. Isla considers her son's freedom and autonomy to be of paramount importance. Motivated by the desire to do what is 'good for your family', Isla is determined to maintain a distal quality within this relationship. As a result, Isla states she would not instigate contact with her son, and reasons that she is working to maintain his freedom: 'if I didn't ring him, then I wasn't bothering him'. Later in her interview, Isla returned to the same topic and reiterated her views on independence, support, and the need to maintain autonomy of others:

Isla: *I mean, you know, my son will say to me when I'm up there, he'll say, "Well, are you sure you're all right, Mum?" "Yes, I'm fine", "Well, your chest doesn't sound very good", "I'm okay, I'm all right". You know, I prefer to be like that, you see, rather than a bit of a bother.*

Int: *No, that makes sense, yeah.*

Isla: *It's just the way you are, isn't it? It's just the way – I've always been the same; independent. But independence is a good thing, I think.*

Int: *Yeah, okay.*

Isla: *I think, you know, you need a certain amount of independence. I could not bother anybody more than I needed to do.*

Isla, 2nd Interview

In the above exchange, Isla defines her independence as a morally virtuous quality: 'independence is a good thing'. Further, the virtue of independence is premised upon the notion that to ask for (or to receive) support from others is inappropriate or improper in some way. Isla states that 'I could not bother anybody more than I needed to do', affirming the moral impropriety involved in seeking and receiving support. In this sense, we might recognise the impropriety involved in 'bothering' other people as concerned with making claims upon other peoples' time, their energy, and their lives in general. For Isla, independence is a 'good thing' because it maintains the freedom and autonomy of the people she loves.

The theme of other peoples' autonomy and freedom was common to several participants' reflections upon independence. This theme was emphasised particularly by the language participants' used to describe supportive relationships. A phrasing adopted by many participants was that of the 'expectation' made upon others; participants sought to demonstrate that even in close supportive relationships, they did not 'expect' others to provide support:

So they're there for us, I mean, they ring virtually every day, but you know, I wouldn't expect them to, sort of, get on their bikes and come up at the drop of a hat. I mean, you know, it won't be like that.

Ian, 1st Interview

Yeah, I wouldn't expect anybody to, to come and [coughs] – excuse me – to look after me full time.

David, 2nd Interview

Well we – we do watering for each other and that's, we don't – we don't expect anything else really you know.

Pamela, 1st Interview

In the above quotations, each participant reflects upon supportive relationships and states that they do not 'expect' support from others. Each participant spoke about expectations in terms of specific relationships and with regard to particular forms of support. In the above quotations, Ian associates expectation with the onerous requirements of giving support ('get on their bikes and come up at the drop of a hat'); David considers the commitment of others and the prospect of 'full time' support; whilst Pamela concludes that gardening support (understood to be relatively inconsequential) marks the limit of what may be 'expected' of her neighbours. Each of these statements forms an appraisal as to what form of support (in terms of the meaning or value) may be appropriate or reasonable to accept within particular relationships. However, a key point here is that each participant stresses the absence of 'expectation'. The phraseology of expectation is significant as it highlights that to expect of another is to oblige or demand them to concede their freedom and autonomy. In the above quotations, each participant recognises the meaning or value of particular forms of support (care at the 'drop of a hat', long-term care, gardening), and each make statements that they would not oblige or make claims upon others in this way. Accordingly, these statements may be recognised as performances of moral propriety; participants demonstrate that they understand what is acceptable to claim or accept from others.

In summary, participants identified independence, almost universally, in moral terms as 'a good thing'. Dependence was identified in similarly universal terms as undesirable or

improper. Further, where dependency was discussed – either explicitly or implicitly – it was addressed in terms of the consequences for other people (freedom and autonomy of others).

8.3 Ethical work

A second claim of this chapter is that people living with illness, cognisant of the moral principles of independence and dependence, enter into a multitude of dispositions and actions which may be termed ‘ethical work’. Ethical work may be understood to refer to any practice or mind-set engendered by a desire to do ‘the right thing’ or what is ‘proper’ concerning the receipt of support and assistance. This section details forms of ethical work as identified by participants, and describes the ways ethical work shapes supportive relationships and the notions of the Self during receipt of support.

Given what has already been stated regarding independence and dependency, it is of little surprise that a fundamental form of ethical work concerns participants’ efforts to avoid seeking support. Isla, for example, revealed a strong compulsion to work hard at managing her illness alone, rather than involving her son in a supportive capacity. During her second interview, Isla stated that she had previously refrained from contacting her son when she needed support:

Int: *Am I reading too much into it to think then – so would you put off asking for help?*

Isla: *Yeah.*

Int: *You’re smiling.*

[Laughter]

Is that something that has happened in the past?

Isla: *Oh yes.*

Int: *Right, okay. Can I ask you about that then?*

Isla: *Well I had this funny kind of – I don't like bothering anybody. If I can work it out I will – to my cost sometimes - I'm not always right. I've always never wanted to lean on him, if you know what I mean. I've never wanted to encroach on his life.*

Isla, 2nd Interview

Isla states that her desire to remain independent has, in the past, resulted in her suffering alone rather than seeking help. Isla relates these efforts with her desire not to make claims upon other people; 'I don't like bothering anybody'. Isla interprets the supportive relationship as one which limits the freedom of others, and she considers this to be unacceptable. This issue is particularly salient for Isla with regard to her son, whose life she does not wish to 'encroach upon'. As Isla spoke about her relationship with her son, she began to cry; however, after some time, Isla returned to the same topic:

Isla: *It was just one of those things with me. I like to try and be independent, to live my own life like I always have. But she went [a former friend] – my husband died and she's 76 [neighbour] and of course XX [deceased son] was here then. And when XX died [deceased son], I didn't want him [living son] to have all the responsibility.*

Int: *So you'd rather do it yourself and...*

Isla: *Yeah, yeah. He [living son] used to get on the phone to me and say, 'Why didn't you tell me? Why didn't you let me know?'. Because I should, but I never did, never did. Now I have to. It's a different situation now.*

Isla, 2nd Interview

Isla describes her social network and how, in recent years, she has lost a number of important friends and family. Most significantly, the deaths of her eldest son (as a child) and her husband have had an enduring affect upon her relationship with her remaining

son. Isla's abiding objective (as during his childhood) is to ensure that her son's life is not oriented towards her, and that he does not feel responsible for her wellbeing. As a result, Isla considers it preferable to remain detached and to struggle alone rather than to involve her son in support. This may be recognised in practical terms as a form of illness self-management; however, it should also be recognised as an instance of ethical work: Isla works hard to maintain the independence and freedom of her son. Isla concludes by reflecting upon her current situation and the fact that her illness means she can no longer eschew supportive relationships. The prosody of Isla's voice conveyed a sense that she had come to accept this situation, but that she remained ambivalent about the future and the supportive aspect within her relationship with her son. This example reveals a particular form of suffering; Isla works towards satisfying the principle of independence and dependence, however her deteriorating health means that she is forced to confront the prospect of transgressing these same principles.

For the majority of participants, living with multimorbidity meant that support was an everyday occurrence. Despite being commonplace, however, even incidental or apparently mundane examples of support were often described in moral terms. Indicative of this was the way that participants spoke about how they 'ought' to feel or behave in response to support. Rose, for example, spoke of conflicting emotions with regard to her supportive family:

...they're in touch with me all the while... I don't get a lot of peace...it sounds ungrateful but there's times when I think. "Oh, I'll have half an hour now", and somebody comes in. Still, I should be grateful really.

Rose, 1st Interview

Rose experiences her family's efforts to support her as somewhat stifling and intrusive; however, she feels uncomfortable with the fact that she harbours these feelings. Rose states that she 'should be grateful', and that speaking about her annoyance 'sounds

ungrateful'. These comments reveal an ideal affective response to the receipt of support: the feeling of gratitude. Rose feels uneasy about falling short of this ideal response and challenges herself to feel differently, castigating herself for feeling ungrateful. In this instance, we see a form of ethical work which involves the management of emotions and feelings according to what is morally decorous. In a further example, Isla described her experience of receiving advice and support from a neighbour (a nurse):

She came in last week – oh I did ask her advice – my son thinks I need a hearing test and I wanted to know what the procedure was. She just popped in to tell me what you do; the stages you have to go through.

Isla, 2nd Interview

Having described this instance of support, Isla continued to detail how she felt she should conduct herself in receipt of this support:

Isla: *We did talk about that and, you know, she just said, 'if you ever want any help in that, you know, let me know.' But, you know, you've got to be careful because you've only got to say to somebody, 'XX [nurse neighbour] was very good and she did....' They could go on from there and she wouldn't want that, would she? I mean - you know.*

Int: *So other people?*

Isla: *Other people yes, yeah. You've got to be careful how you – I would keep it confidential really that she spoke to me about it, you know.*

Int: *Is that because you would just be – you wouldn't want....*

Isla: *I wouldn't want everybody ringing her up and saying, 'can you help me with this or can you help me with that?'*

Int: *Because of what she might think.*

Isla: *Yes, yeah, yeah. I wouldn't like that – no.*

Isla, 2nd Interview

Isla feels as though the appropriate response to this instance of support is to maintain some form of confidentiality. Isla makes no suggestion that the issue of confidentiality was discussed with her neighbour; rather, I understood confidentiality to be something Isla felt to be appropriate only intuitively. The importance of confidentiality in this example is likely associated with the identity of the support giver – a nurse who provides her professional expertise outside of the formal professional domain. Isla recognises how useful this support is, and she does not want her neighbour to become overburdened with similar requests from others. Whereas Rose's (above) example concerns a purely affective response to support, Isla's example illustrates that ethical work may also require more practical efforts. In the examples of Isla and Rose we see how, for people living with illness, the receipt of support is rarely a morally neutral event. Both Rose and Isla are aware of an appropriate response to support, and both strive toward feeling or enacting these responses. Further, these examples illustrate just what an involved process ethical work is, and the degree to which the principles of moral authenticity guide dispositions and actions during the receipt of support.

For many participants, the most common instances of ethical work concerned efforts to remain active providers of support to others. In such cases, participants identified supportive relationships as mutually beneficial to all involved; the notion of reciprocity was invoked regularly as an indication of this mutuality. David, for example, spoke about his relationship with his neighbours and the degree to which he was able to call upon them for support. In describing these supportive relationships, David provided an example of reciprocal exchange which, although somewhat peculiar, captured an important sense of mutuality:

David: *I don't go round there drinking coffee and what else have you, like... I don't want that myself. But if I buy a pair of trousers and they want shortening, I put them in a bag, hang them on the fence and then two days later they're back on the fence again, I bring them and they've been done.*

Int: *Really, that's good.*

David: *It doesn't cost anything.*

Int: *No, right. Do you feel as if you - do you have - do you do stuff in return?
Or is ...*

David: *Yeah.*

Int: *Or is it that they're just happy to do it, kind of thing?*

David: *Oh, they're happy to do it. But I get certain things given me in the food line, you know. I come in a week or two back and I got two bloody great big Savoy cabbages. I like cabbage. I can't manage them two so I give one to [gestures towards neighbour's house] you know.*

David, 2nd Interview

David explains that this neighbourly relationship is not particularly close – 'I don't go round there drinking coffee'. David also details the reciprocal exchange of favours; whilst these favours are important to David we might recognise that, when compared to some forms of support, they lack significant value (as conceptualised in the previous chapter). This example is typical of the ways in which reciprocity was identified by participants: relatively weak relationships (acquaintances and neighbours, for example) where the reciprocal exchange of support concerned relatively minor or incidental acts. A similar dynamic is apparent in Pamela's discussion of neighbours and support:

They came over and helped me dig up my borders and pot things up and I said, and they took things home with them you know. So she's took some plants up to XX (North) and XX has got plants there and then I helped her actually plant them in her garden as well so yeah we – we have a good relationship with the neighbours and – and, yeah they're very good yeah.

Pamela, 1st Interview

Pamela's example bears a number of similarities to that of David (above) in that the type of support described (gardening) may be understood to have relatively little inherent meaning or value (in terms of symbolic, semiotic, or economic meaning). Despite her illness, Pamela is able to reciprocate co-operation and provide similar support to her neighbour. The ability to reciprocate support is important for Pamela, and contributes towards her evaluation of this relationship as successful: 'we have a good relationship'. In another example, Bill and his wife (Cath) identified the role of neighbours in similar terms. Bill detailed how certain neighbours would provide transport or assist in manual tasks, Cath then stressed that these supportive relationships were not one-directional:

Cath: *The lady next door, it works both ways, she's got a car and he's got a car. Now, if she's not very well, you've [Bill] taken her to the doctor and different places, haven't you...?*

Bill: *Yeah*

Cath: *...you know, it just works one with the other.*

Bill and Cath, Bill's 1st Interview

This relational dynamic was reiterated by Cath later in the same interview:

Cath: *If somebody's poorly, or wanted to go somewhere, the hospital or the dentist...*

Bill: *I usually can take them and...*

Cath: *...or whatever, he jumps in the car and takes them.*

Bill and Cath, Bill's 1st Interview

In a similar way to Pamela (above), Cath considers the reciprocal dynamic of neighbourly relationships to be important; she suggests reciprocity is key to these relationships functioning successfully – ‘it just works’. The above examples share common features. Firstly, the relative strength or emotional proximity of these relationships determines, to a large extent, what forms of support are exchanged. In the above examples, weaker relationships (relative to the strength of family or closer friends) sustain only modest forms of support and assistance. Secondly, the nature of these relationships means that the act of reciprocation assumes increased moral significance. In such relationships, the lack of any institutionally constituted obligation to support (as might be the case in a parent-child relationship, for example) means that the impropriety of unreciprocated acts is amplified. In contrast to institutionalised relationships, neighbours and acquaintances enter into such relationships freely. As a result, these social ties are experienced as more contingent, and there is a tacit expectation that these relationships should be mutually gratifying; it is for this reason that participants identified reciprocity as important. In demonstrating their reciprocation of support, the above participants present themselves as attending to the moral assumptions of neighbourly relationships. This proposition is supported by Pamela and Cath’s assertions that reciprocity contributes to successful or well-functioning neighbourly relationships.

The notion that the supportive actions should be repaid was not limited to discussions of reciprocity. For some participants, illness and disability meant that direct reciprocation of support was impossible. In such cases, the same moral precept of mutuality was apparent in slightly modified forms. Isla, for example, was unable to reciprocate the domestic and transport support she received from friends and neighbours. During her second interview,

while discussing the prospect of paying for formal support, Isla stated that she had recently employed a professional cleaner rather than relying upon her neighbour for support:

Isla: *I get a disability allowance, you see, so I use it for that purpose.*

Int: *So you now pay this new cleaner and did you pay the neighbour?*

Isla: *No, no, no. I do it in kind, in different ways.*

Int: *How do you mean?*

Isla: *Well, as it's her birthday next week I shall put money in the envelope for her.*

Isla, 2nd Interview

Later in the interview, I pursued this issue further with Isla:

Int: *You said, 'I'll pop some money in the birthday card or whatever.' I was just wondering what you meant by doing something in kind. What kind of thing did you mean?*

Isla: *Well, it's very difficult with Penny [neighbour/friend]. She's not very good at accepting presents or anything like that and she's a bit difficult. So the only way I can do it is – I mean I have – when she used to clean for me, I used to put an extra £10 in a – and she'd always give it me back, you know. She's very difficult to really– and you can only really do it to people like Steven [male friend] and Liz [female friend], who take me to church every week. I couldn't give them any money for petrol but, of course, I buy them an extra special present. That's the only thing – that's the only way you can do it.*

Int: *That makes absolute sense, and is that important for you?*

Isla: *Oh yes. Well, it's very difficult to show appreciation. You can do it verbally and say, 'Thank you very much' as many times as you like, but you don't feel as if you're rewarding them enough. But then if, if I was in that position I'd probably be the same. But Penny is very difficult to reward, as you might say. I feel with Sandra [paid cleaner], who cleans for me, I feel what I give her is adequate. I don't feel for one moment that I'm not paying her, you know, for what she's doing. But I don't mind – it's probably over – more than shall we say the going rate, if that's – but I don't mind that because the work's done to my satisfaction.*

Isla, 2nd Interview

The above exchange highlights the importance of repaying or rewarding others for acts of support; Isla wishes to demonstrate gratitude to others by rewarding their benevolence. However, as Isla details, her efforts to reward and repay are complicated by the fact that her friends are reluctant to accept her gestures of recognition, or to accept any direct payment. To resolve these concerns, Isla works to demonstrate her gratitude through subtle forms of repayment, such as giving presents and gifts. Here there are clear parallels with the above examples pertaining to reciprocity, and similar moral precepts appear to be at play. Isla feels it is important to give to others and not be a passive recipient of support: she wishes for these relationships to be balanced.

In summary, the most common forms of ethical work concerned participants' efforts to remain independent and, by avoiding dependence, preserve the independence of others. However, a range of other ethically motivated actions and dispositions have been identified which concern the mutuality of supportive relationships. In its most elementary form, mutuality may be identified in the recognition of supportive acts – feeling or demonstrating gratitude ensures that a supportive act is not entirely one-directional. Mutuality is most apparent, however, in instances of rewarding or reciprocating the supportive acts of others. Just as in economic exchange (where it would be immoral to

renege on the payment of others), it is ethically dubious to engage in social relationships which are not mutually worthwhile in some sense. Demonstrating gratitude, giving gifts, and reciprocating the benevolence of others is an important part of recognising the supportive other as a dignified person. Such actions of mutuality also enable the person in receipt of support to feel as though they too are a morally authentic subject.

8.4 Co-dependence

The moral precepts of independence, dependence, and mutuality were ubiquitous in participants' discussions of support and assistance. However, some participants identified certain relationships as transcending these concerns. Married participants spoke often about their partners and the spousal relationship as a qualitatively unique form of supportive relationship. Ian, for example, spoke about his relationship with his wife in these terms:

All my family are in different parts of the country and different parts of the world. So I'm not a, you know, I'm not local to this, to this part of the world. Obviously, it's a bit of a concern, because there'll come a point in time when you know, you have to decide what, you know, what, whether you can continue to look after yourself, or look after one another. So, you know, I'll be dependent upon my wife, she'll be dependent upon me. That's, that's, that's the way it's going to be.

Ian, 1st Interview

Earlier in his interview, Ian spoke about the fact that he had an extensive local network of friends which enabled him to lead a rich and varied social life. However, in the above excerpt, Ian states that he does not consider these friends to be a viable source of support given his deteriorating health. Ian identifies that his single most important supportive relationship is that of his wife. What is particularly interesting in this example, however, is the ease with which Ian confronts the prospect of dependency, stating – 'that's the way it's going to be'. Clearly, the meaning of dependency within this particular relationship is

different to dependency as imagined in any other (acquaintances, neighbours, friends, even one's children). For Ian, this relationship is one in which dependency is modified into co-dependency: 'I'll be dependent upon my wife, she'll be dependent upon me'.

Similar sentiment was apparent in Theo's discussion about his wife and the supportive aspect of their relationship. Theo explained how, despite his wife's very extensive local friendship network, neither he nor his wife looked beyond one another for meaningful support and assistance:

Int: *So in terms of getting help from other people, is it mostly between the two of you then?*

Theo: *Yeah, yeah. Because we have our own means of transport. I mean we've got the car there so if I wanted to go to the hospital now, a stroke, or if she wanted to go to the hospital, we're in the car and gone before anybody knows about it. So we are – we depend on each other a great deal because – well there's no kids here and there's no other people and then we tell the neighbours or what have you. But basically we depend on each other.*

Theo, 2nd Interview

Theo describes his relationship with his wife in terms similar to those described by Ian (above). The co-dependency between Theo and his wife is heightened by the fact that their two sons live a great distance away. In this example, Theo presents co-dependency as a form of self-sufficiency; through co-dependency, Theo and his wife are able to remain independent from other people – 'we're in the car and gone before anybody knows about it'. As in the case of Ian, Theo appears comfortable with the prospect of dependency when it occurs within a relationship of co-dependency. Elsewhere in participants' interviews, participants spoke about marriage as being akin to a 'team' rather than being two distinct individuals. In the examples of Ian and Theo (both of whom had been married approximately 40 years) the spousal relationship is one where the distinction between

individuals has, to an extent, become blurred. In these cases, the principles of independence and dependency were less pronounced to the degree that they were seemingly irrelevant.

8.5 Discussion

This chapter has outlined the ways in which the receipt of support and assistance is experienced as a moral practice. In detailing the experiences of participants living with multimorbidity, this chapter has identified a number of moral principles which shape the meaning of support. While these principles may be seen to be related, it is useful to characterise them in three distinct forms.

- Firstly, the principle that one should be independent, self-sufficient and in control of one's own person.
- Secondly, the related principle that dependence upon others must be avoided. It has been argued that this principle is based upon the notion that one should not make claims towards the freedom and autonomy of others.
- Thirdly, where supportive exchanges do occur, the supportive relationship must retain a degree of mutuality.

Having identified these aspects of morality, this chapter presented participants' accounts of striving towards these ideals. The ways in which participants sought to meet these ideals – through dispositions and actions – has been termed 'ethical work'. The term 'work' is apposite given the energy, effort, and deliberation required to feel and act according to such principles during illness. However, to address these issues in greater depth and clarity requires a more thorough consideration of morality in sociological terms. What this means is attending to questions such as: what is morality? How should we understand the function of morality? And what are the consequences of morality for people in receipt of support?

It has been argued (within this thesis' theoretical review chapter and throughout this chapter) that the moral mechanism of reciprocity is insufficient to account for morality within supportive exchanges – the data presented in this chapter supports this assertion. However, further normative theories of ethics – including virtue theory, duty theory, and consequentialist ethics, also seem ill-equipped to account for the complex intersections of morality, the relationship between self and other in exchange, and the gamut of embodied and existential threats posed by illness. In contexts such as this, the logical rigor of moral philosophy seems at odds with the messy reality of support during illness. These tensions are reflected in Taylor's comments as to the limitations of moral philosophy:

...moral philosophy has tended to focus on what it is right to do rather than on what it is good to be, on defining the content of obligation rather than the nature of the good life; and it has no conceptual place left for a notion of the good as the object of love or allegiance (Taylor, 1992; 9).

This chapter has illustrated that for participants in this study, what it means to be good and to lead a good life (in short, what it means to be an authentic moral subject) during the receipt of support is intimately tied to the notions of love and allegiance. This is why, perhaps, it seems somewhat insufficient to speak about the principles of independence, dependence and mutuality simply in terms of obligations or duty – duty and obligation fall short in both descriptive and explanatory terms. A more appropriate way to consider the dynamics of morality during the receipt of support may be gleaned from Foucault's writings on ethics. Foucault was not concerned with identifying or describing moral codes and edicts; rather, he sought to identify the role of morality in shaping the relationship between the individual and the Self. In this regard, Foucault's ethical project was consistent with his wider theoretical positions on governmentality and the disciplinary 'technologies of the self'. Accordingly, Foucault presented morality not as prescriptive rules, obligations, or duties *per se*, but as the starting point for the ethical work undertaken by the individual in the production of the Self as a moral subject. The following excerpt is

taken from *The History of Sexuality* (volume 2) and outlines Foucault's approach to morality:

All moral action involves a relationship with the reality in which it is carried out, and a relationship with the self. The latter is not simply "self-awareness" but self-formation as an "ethical subject", a process in which the individual delimits that part of himself that will form the object of his moral practice, defines his position relative to the precept he will follow, and decides on a certain mode of being that will serve as his moral goal. And this requires him to act upon himself, to monitor, test, improve, and transform himself (Foucault, 1985: 28).

From this perspective, moral and ethical action is concerned less with extraneous duties, obligations or rules, and speaks instead to the principles around which the individual knows the Self as ethical or good. Recalling Taylor's claim that morality must be understood in terms of *what it is good to be*, rather than just *what it is good to do*, it is useful to think of morality in Foucauldian terms as the ethical action we undertake to make us the kinds of people we want to be. This sentiment accords with the ways that moral principles were represented by participants in this study. Participants did not discuss the morality of receiving support in terms of duties or obligations as such, but rather, they did so in terms of how they wished to be recognised by loved ones and by themselves – as independent, as not being dependent, and as active participants in relationships of mutuality. While this is a useful way to consider the functional workings of morality, it does little to further our understanding of the specific moral principles identified in this chapter. More may be said in this direction.

The finding that independence is considered virtuous and dependence aberrant is not entirely novel, and has been identified elsewhere in critical gerontology and disability studies (Breheny and Stephens, 2009, 2012; Rozanova, 2010). However, much of this commentary assumes that the principles of independence and dependence function

through the stigmatisation of support as a representation of idleness, malingering, or being at odds with the 'Occidental story' that there is always work to be done (DeCerteau, 1998: 190). While this may be true in part, it is the contention of this thesis that the principles of independence, dependence and mutuality speak to yet more fundamental human concerns. Specifically, these principles concern what it means to be an individual in liberal democratic thought. In this respect, the three principles identified within this chapter bear striking affinity and similarity to literature within social and political thought concerning the relationship between individualism, liberalism, and capitalism. For example, the themes of independence, dependence, and mutuality are recognisable in the concept of 'possessive individualism' as contributed by C.B. Macpherson (1962).

In what is now a seminal text of contemporary political theory, Macpherson (1962) traces the historical development of economic, social, and political theory from the inception of seventeenth-century liberalism to modernity. In doing so, Macpherson claims to identify a particular form of 'possessive individualism' specific to capitalist liberal democracies. Whilst a thorough discussion of this concept is beyond the remit of this chapter, Macpherson's analysis of possessive individualism warrants further quotation as it illuminates the perspectives offered by participants in this chapter. Concerning the historical taproots of possessive individualism, Macpherson states:

Its possessive quality is found in its conception of the individual as essentially the proprietor of his own person or capacities, owing nothing to society for them. The individual was seen neither as a moral whole, nor as part of a larger social whole, but as an owner of himself. The relation of ownership, having become for more and more men the critically important relation determining their actual freedom and actual prospect of realizing their full potentialities, was read back into the nature of the individual. The individual, it was thought, is free inasmuch as he is proprietor of his person and his capacities. The human essence is freedom from dependence on the wills of others, and freedom is a function of possession. Society becomes a lot of

free equal individuals related to each other as proprietors of their own capacities and of what they have acquired by their exercise (Macpherson, 1962: 3).

Macpherson argues that the development of liberalism, from Hobbes to Locke, has witnessed a movement towards conceiving of the individual as defined through possession in ideal and material senses.³³ Macpherson extends this insight and identifies the role of possessive individualism in allowing liberalism to flourish alongside private enterprise and the capitalist mode of production. Macpherson's contribution is not, however, one of purely historical analysis and his work concerns the construct of the liberal individual in contemporary terms. In concluding his thesis, Macpherson provides seven axioms of possessive individualism – three of these axioms concern particular economic, political, and macro-social spheres, and are less relevant to this chapter. Four of Macpherson's axioms, however, resonate immediately with the moral principles identified and alluded to by participants in this chapter:

- 1) *What makes a man human is freedom from dependence on the will of others*
- 2) *Freedom from dependence on others means freedom from any relations with others except those relations which the individual enters voluntarily with a view to his own interest*
- 3) *The individual is essentially the proprietor of his own person and capacities, for which he owes nothing to society*
- 4) *Since freedom from the wills of others is what makes a man human, each individual's freedom can rightfully be limited only by such obligations and rules as are necessary to secure the same freedom for others*

(Macpherson, 1962: 263).

³³ Macpherson was an ardent critic of this mode of individualism, and the above axioms are the outcome of an analysis into what he considered a malaise within contemporary liberalism.

Accordingly, the possessive individual is defined through self-proprietary and by freedom from dependence on the will of others. Freedom is sacrosanct and relations which threaten to compromise this autonomy are to be guarded against as a direct threat to the status of the individual. For the purposes of this thesis, Macpherson's critique invites us to re-consider the moral principles of independence, dependence, and mutuality as identified within this chapter. Rather than considering these principles in terms of stigma (support as meaningful by its associations with stigmatised representations of idleness and malingering) or with virtues such as stoicism, we might more productively recognise these principles as foundational to the constitution of the individual in liberal society. From this perspective, the ethical work described by participants in this chapter concerns not only the desire to be recognised as virtuous, but is also a means towards preserving and asserting their status as individuals. Further, the meaning of ethical work towards preserving the autonomy of friends and family assumes yet more significance as it concerns the preservation of loved ones' 'human essence' (to use Macpherson's term) as free individuals. The credibility of this argument is underscored by reference to those participants for whom independence and dependence were not salient concerns. In this regard, where participants described marriage and the supportive aspect of spousal relationships, the principles of independence and dependence were less pronounced (to the point of being irrelevant). This is understandable given that in such relationships the individual is not defined in strictly delimited terms, but rather, as an individual in the world with another; co-dependency inheres not just in the practices of support, but also in the formation of Self. Accordingly, where participants reflected upon supportive spousal relationships, they did so from a position whereby their (and their partner's) status as an individual was less contingent upon the possessive qualities of freedom and self-proprietary.³⁴

³⁴ Or at least these qualities (as constituent features of the individual) are diminished within the dynamic of a 'team' (participant and spouse as a self-sufficient partnership). It might be argued that such relationships are a form of possessive dualism whereby the same principles of independence,

In summary, chronic illness has been described insightfully by Charmaz (1983) as a 'fundamental loss of self'. This chapter affirms such a viewpoint, but would add that the moral principles and ethical work described by participants in this chapter attest to a particular kind of loss: the Self and Other as possessive individuals. In a society which considers freedom and the individual to be the very substance of 'what is good', the principles of independence, dependence, and mutuality come to exert a powerful influence over the experience of support during illness. These concerns must also be understood as a particular form of social suffering. For the participants in this study, the realities of living with multiple chronic illnesses meant that remaining independent from other people was an increasingly unrealistic prospect. The notion that 'independence is a good thing' is as much an aphorism as one is likely to encounter; however, for several participants in this chapter, the unattainable nature of this maxim constituted one of illness's crueller ironies.

dependence and mutuality remain relevant to others outside of this relationship (with regard to children and friends, for example).

Chapter Nine: Discussion

9.1 Introduction

In this final chapter, key findings from preceding chapters will be drawn together and the central narrative of this thesis made clear. General themes and specific issues raised in the Literature Review and Theoretical Review will be recalled, and in doing so, this thesis will be situated in terms of its contribution to knowledge. The implications of this study for health and social care policy and practice will be considered and discussed. Finally, avenues for future research will be proposed.

9.2 Reflecting upon findings and research questions

This thesis is concerned with two distinct but related issues: the ways in which multimorbidity is understood to be meaningful by lay participants, and the meaning of supportive practices among lay people living with multimorbidity. Following the literature review chapter, this thesis established two exploratory research questions:

- How do people living with multimorbidity make sense of illness and understand their experience of illness as meaningful?
- How do people living with multimorbidity experience social resources, and how is the receipt of support and assistance understood to be meaningful?

These questions address distinct areas of policy and practice. On the one hand, the need to understand how people living with multimorbidity understand and make sense of illness speaks to the emergence of multimorbidity as a major population health concern which places increasingly complex demands upon health systems and the management of patients in primary care. In a separate development, the emergence of social connectedness as a key theme within health and social care policy and practice requires that processes of social exchange are better understood. Therefore, whilst social

connectedness is important in shaping the experience of multimorbidity, the insight delivered by this thesis is also relevant to the experience of support and assistance during illness more generally. The following sections will outline the findings of this study with respect to each research question before drawing together findings and discussing the implications of this thesis.

9.2.2 How do people living with multimorbidity make sense of illness and understand their experience of illness as meaningful?

This thesis has made the general argument that people living with multimorbidity often understand and make sense of illness in ways that are at odds with a biomedical perspective. Specifically, it has been argued that they make sense of illness according to distinct logics of meaning. These logics refer to frameworks of meaning derived from individuals' engagement with, and enactment of, the motifs of normality, control, biography, and biomedicine.

In this respect, findings from this thesis support and advance those made by recent studies into the lived experience of multimorbidity (identified within the Literature Review of this thesis: Hurd Clarke and Bennett, 2013; Ong et al., 2013; Pickard and Rogers, 2012). This thesis affirms Pickard and Rogers' assertion that multimorbidity is experienced as a 'variegated but unified existential state' (Pickard and Rogers, 2012: 112) – lay people make sense of multimorbidity accordingly to multiple (sometimes contradictory) logics of meaning which are experienced and expressed under the unifying rubric of the individual Self. This general finding poses specific questions in terms of how multimorbidity is understood: is it possible to speak of an 'experience of multimorbidity' in any unitary way? How can might such a variegated but unified experience be accommodated within healthcare systems designed towards treatment and management of single conditions? The Literature Review of this thesis reported that multimorbidity is defined in clinically informed literature as 'co-existence of two or more long-term conditions in an

individual' (Mercer et al., 2009). This concept has been heralded as a 'more democratic' approach towards conceptualising illness (in contrast to the concept of co-morbidity) (Valderas, Mercer and Fortin, 2011). However, the accounts provided by participants in this study suggest that conceptualising illness in this way makes (at least) two unsatisfactory assumptions about the lay experience of multimorbidity.

Firstly, the notion that multimorbidity is defined by distinct diseases, conditions, syndromes, or by other neatly delimited episodes of illness. Participants in this study did not identify or describe their experience of illness in these terms. Where participants did speak about specific conditions, they did so because some aspect of the illness experience – be that a symptom, medication, physical limitation, future risk etc. – propelled that particular condition into the forefront of experience. For many participants, however, the experience of illness could not be explained by reference to clinically diagnosed conditions. Several participants identified the importance of conditions for which they had not received a clinical diagnosis; others described illness in diagnostically ambiguous ways (one participant identified 'coffee granules' as a salient health concern); several participants identified acute illnesses as disruptive and debilitating; others experienced unexplained or un-attributable symptoms; whilst for many, illness was understood primarily in terms of its impact upon personal and social worlds. These observations make clear the biomedical emphasis of multimorbidity (as defined within clinically informed literature) upon a disease model of illness (according to which illness is defined reductively as the dysfunction of various biological forms, with diseases existing as distinct entities (Atkinson, 1988: 180). Accordingly, multimorbidity as a biomedically informed concept privileges the identification and enumeration of diseases as distinct entities, and does so in neglect of the social, cultural, and biographical spheres which underpin the lay experience and meaning of multimorbidity.

Secondly, data in this study suggested that from the lay perspective, the concept of concurrency may be somewhat erroneous. Some participants stated that they

experienced conditions in a singular fashion rather than as immediately co-occurring. Other participants questioned the label of concurrency on biographical grounds; participants for whom long-term conditions had been a part of everyday life for many years (particularly congenital conditions) did not recognise associated symptoms, therapies, or physical limitations as a co-occurring condition per se. Rather, where such conditions were consistent with an individual's biography and did not threaten their accepted mode of normality, conditions were incorporated into everyday life and were not experienced as concurrent in any manifest sense. In view of these findings, it is important to recognise that the lay experience of multimorbidity may not be characterised by concurrency as imagined biomedically. To understand lay concurrency, concurrency must be understood as framed by biography, and in terms of whether or not, and how, illness, conditions, and symptoms come to be salient in the lives of individuals.

Following these observations, a key finding of this thesis is that multimorbidity as currently conceived in clinically informed literature may not accord with the lay experience of multiple chronic conditions. Given this claim, the question must be posed as to how multimorbidity ought to be conceptualised in order that lay experience is better represented? One perspective – alluded to in Chapter Four – more attuned to the experiences described by participants in this study may be gleaned from Paterson's widely cited shifting perspectives model (2001). This model argues against the trajectory model of chronic illness (illness depicted as a phased process wherein the individual follows a predictable trajectory). Rather, according the shifting perspective model:

Living with chronic illness is an on-going, continually shifting process in which people experience a complex dialectic between themselves and their "world"... As the reality of the illness experience and its personal and social context changes, the people's perspectives shift in the degree to which illness is in the foreground or the background of their "world"

(Paterson, 2001: 23).

This thesis does not seek to apply Paterson's model in a rigid or deterministic way, rather the shifting perspective model acts as a sensitising concept which reminds us of the contingent and dynamic nature of illness experience, and the links between illness and personal and social context. Paterson's model asks us to be critical of the trajectory model of illness; a critique which may be usefully extended to the biomedical principles of multimorbidity. Firstly, multimorbidity as a model of illness considered in additive terms whereby illness is defined through the delineation and enumeration of discrete conditions. The findings of this thesis highlight the reductive nature of such an approach, and emphasise that the lay experience of multimorbidity cannot be understood in such terms. Participants in this study described experiences in which long-term conditions or episodes of illness had been incorporated into their everyday lives and which were, consequently, not particularly salient or disruptive; in contrast, some participants identified unexplained symptoms or illnesses which had not been clinically diagnosed as disruptive and dominating their daily lives. Secondly, the shifting perspectives model highlights the link between illness and contextual factors – be they contextual factors relating to the environment, individual psychology, socio-cultural, or economic. Context, according to Paterson's model, affects how, and when, the inward and outward signs of illness shift in, and out, of prominence during the individual's experience. This thesis has argued that multimorbidity, as informed by clinical literature, is often premised upon a mode of concurrency which is static and atemporal. The accounts provided by participants in this study highlight that the lay experience of multimorbidity must be recognised as historical, temporal, and biographical. These arguments accord with those advanced by Paterson (2001), and would support a reading of multimorbidity in terms of how and why illness, or wellness, come to be foregrounded in individual experience.³⁵ This thesis has begun to

³⁵ Paterson defines a 'perspective' as the 'beliefs, perceptions, expectations, attitudes and experience about what it means to be a person with a chronic illness in a specific contexts' (Paterson, 2001: 23). According to Paterson's model, the perspective of people living with chronic illness may be understood in terms of whether illness or wellness assume position in the foreground of individual experience. Paterson identifies the 'illness

answer this question, and has identified several ways by which people living with multimorbidity make sense of multiple chronic conditions.

Many participants identified normality and control as important factors which shape and transform the impact and importance of multimorbidity. This finding is consistent with recent studies identified within the literature review of this thesis. In particular, Cheraghi-Sohi et al. (2013) illustrate the role played by 'self-perceptions of control' in defining the importance of particular conditions during multimorbidity. Control, however, does not simply relate to the control exerted over one's body and the symptoms of illness (although these are the principal registers of control). Rather, control also pertains to the individual's knowledge of illness and, to use Bury's conceptualisation, being able to 're-establish credibility in the face of the assault on self-hood which is involved' (Bury, 1991: 456). Control, in this sense, pertains to actual or perceived control over the self. In this study, participants spoke about their efforts to gain and maintain control over their bodies, the symptoms of illness, the self and their social worlds; each of these representing a site of normality at risk during multimorbidity. Where participants were able to exert control over their illness, their bodies, and their lives, normality was a realistic prospect and, to use Paterson's terminology, wellness came to be foregrounded in experience. By contrast, where control was not possible, normality seemed a remote prospect and illness was propelled into the foreground, dominating individuals' personal and social worlds.

in the foreground perspective' as 'characterized by a focus on the sickness, suffering, loss, and burden associated with living with a chronic illness; the chronic illness is viewed as destructive to self and others' (Paterson, 2001: 23). By contrast, the 'wellness in the foreground perspective' is one in which 'the self, not the diseased body, becomes the source of identity. The body becomes something to which things are done, not what controls the person... Distancing from sickness allows for a focus on the emotional, spiritual, and social aspects of life, rather than primarily on the diseased body' (Paterson, 2001: 24).

Biographical reasoning was also central to how participants made sense of multimorbidity (a finding consistent with that of Lindsay (2009)). Chapter Four identified instances of illness-specific biographical reasoning; OA and cardiovascular disease, for example, were identified by several participants as a 'normal' part of growing old. However, in general, biographical reasoning was highly individualised, and followed personal, social, economic and life course factors as well as illness specific factors. Accordingly, for some, illness was biographically disruptive, whilst for others, biographical reconstruction and biographical flow were evident. Bury's (1982) concept of biographical disruption is helpful in understanding the meaning of multimorbidity for some participants. The advent of certain conditions – particularly conditions or illness events which were new and yet to be understood by the individual – are often experienced as a disruptive event during which cognitive and material resources are thrown into relief and questioned (Bury, 1982: 178). For others, the intersection of ageing and chronic illness meant that multimorbidity was a point of biographical continuity rather than disruption. Faircloth et al. (2004) use the term 'biographical flow' to depict the ways in which illness may be integrated with various other social contingencies and thus construct coherent and consistent biographies. Chapter Five presented case studies of three participants for whom biographical reasoning was central in defining the meaning of multimorbidity in general, and also particular conditions within each participant's multimorbidity. The meaning Mary attached to her recent (and uncertain) diagnosis of diabetes was very different from Theo's understanding of his congenital impairment. For Mary, the sudden onset of illness, enforced changes to her diet, and uncertainty over diagnosis meant that diabetes was biographically disruptive. Theo, by contrast, has always lived with impairment; the knowledge, resources and skills he has developed over a lifetime of disability mean that he is able to incorporate impairment into his everyday life. Clearly, the impact and meaning of illness in these cases is closely related to the biographical context within which it plays out. Biography, therefore, is an important register of meaning for people living with multimorbidity, and

attempts to understand the lay experience of multimorbidity must consider biographical context of paramount importance.

Finally, several participants made sense of multimorbidity by reference to biomedicine, or as a result of interactions with HCPs. For some participants, the meaning of illness was informed by their knowledge of risk and the risk of future illness events; for example, many participants talked about being at increased risk of cardiovascular events as a result of hypertension. For most of these participants, the risk of cardiovascular events was the only perceptible feature of hypertension (given that it was otherwise asymptomatic and controlled through medication). Prognostic knowledge also informed the meaning of certain conditions; cancer, for example, was discussed in terms of mortality whereas diabetes was understood as a chronic condition which could be managed effectively. These observations highlight that the distinction routinely made between expert and lay knowledge is little more than a trope and does not accurately reflect how lay people understand illness. Rather, as has been discussed by McClean and Shaw (2005), knowledge of illness is spectral, not binary, and lay people regularly appropriate, adapt and deploy biomedical knowledge within their own sense making practices. Accordingly, the forms of biomedical knowledge which lay individuals appropriate, and the ways in which this knowledge shapes beliefs and practices, are likely to play an important role in defining whether or not – to use Paterson’s metaphor – illness or wellness come to be foregrounded during an individual’s experience of multimorbidity.

These findings have further implications for the conceptualisation of multimorbidity in academic literature. Early research into the lay experience of multimorbidity identified that, among individuals with common conditions, a discernible pattern to individual experience is often lacking (Bayliss et al., 2003). Subsequent research regarded this observation as a challenge, and a burgeoning literature now addresses the ways in which certain conditions come to be ‘prioritised’ during lay experience. However, this thesis extends the critique of biomedical principles towards the concept of illness prioritisation (Elliot et al., 2007; Kerr et

al., 2007; Morris et al., 2011; Schoenberg et al., 2009). Illness prioritisation, as a concept, risks assuming the same flawed principles which appear in clinically informed multimorbidity literature. Namely, that people with multimorbidity understand illness by reference to neatly delimited conditions, and according to a biomedical model of concurrency. This thesis affirms the early assertion made by Bayliss and colleagues (2003) and cautions against any approach which focuses solely upon condition-specific patterns in lay experience. As the foregoing discussion has set out, the individuated nature of multimorbidity is not an obstacle to be overcome through closer observation and classification. Instead, variegation should be seen as a key characteristic of multimorbidity. To understand the lay experience of multimorbidity is to recognise the manner in which corporal, biographical, and socio-cultural logics intersect to inform meaning in individual cases. This thesis is among the first to argue for such an approach, and makes an important contribution towards how this might be realised.

9.2.3 How do people living with multimorbidity experience social resources, and the receipt of support and assistance as meaningful?

Answering the second question posed by this thesis has been a difficult and involved process, not least because the data presented in this study demonstrates how participants experience support and assistance in very different ways. Participants in this study experienced a wide range of medical conditions and physical impairments; social and economic circumstances were equally diverse. Accordingly, whilst some participants relied upon other people for frequent and regular support, other participants needed very little support and assistance in order to maintain social roles and accomplish valued activities. From an analytic perspective, data appeared difficult to comprehend and categorise.

The diversity of participants' circumstances and experiences was illustrated in Chapter Five. Three participant cases presented the complexity and diversity of participants'

material and emotional experiences of support. In doing so, this chapter also highlighted the difficulties involved in conceptualising social resources according to perspectives which prevail in health sciences literature. Chapter Six was, in part, an explication of my efforts as a researcher to understand various theoretical shortcomings inherent in such perspectives, and to confront and question my own theoretical assumptions (these issues are outlined in greater detail within the reflexive section of Chapter Three and throughout Chapter Six). Hence, chapter Six detailed the conceptual lineage of social capital and individualist social network perspectives. It was argued that these approaches are limited by their reliance upon rationalist models of agency and individualist modes of social action. As redress, this thesis introduced literature from gift exchange (a fundamentally collective form of social exchange) and promoted Baudrillard's (1981) model of value. Gift exchange literature also highlighted the importance of morality in social exchange, a fact which shaped the findings of this thesis further. Specifically, it was argued the concept of reciprocity – which prevails in social capital theory – fails to adequately conceptualise morality and is not sufficient to explain the moral implications of support and assistance during illness.

The final two chapters of this thesis applied the insight delivered in Chapter Six to the interpretation of participant data. Chapter Seven presented participant data and identified the meaning of supportive acts as falling into four logics of value: exchange-value, use-value, semiotic-value, and symbolic-value. These logics were presented individually, before being applied to the analysis of more complex examples of supportive exchange. The term *interpretive economy of meaning* was coined in conceptualising the coalescing and intersecting nature of value forms during supportive exchanges.

Chapter Eight focused upon the role of morality during the receipt of social resources. Through close analysis of participant data, this thesis presented three moral principles common to the receipt of support and assistance. The virtue of independence, the aberrance of dependence, and the need to maintain mutuality within relationships were

identified. It was argued that these principles are not experienced as extraneous rules or obligations, but rather, are central to the individual's understanding of selfhood – what it means to be a 'good person'. The ways in which participants attempted to realise these ideals was termed 'ethical work' (Foucault, 1985) in recognition of the arduous and onerous nature of such moral actions; various practical actions and affective dispositions were identified as examples of ethical work. In discussing these issues, this thesis introduced the concept of possessive individualism (Macpherson, 1962) and posited that the above moral principles are derived from a socio-politically constituted notion of the individual which pervades liberal democratic societies – the possessive individual.

For the purpose of this thesis, possessive individualism (Macpherson, 1962) and ethical work (Foucault, 1985) act as a heuristic aids, sensitising us to the indissoluble relationship between possession; the moral enactment of possession during exchange (through autonomy, self-sufficiency, and independence); and selfhood. Where participants were able to meet the moral principles surrounding independence, dependence and mutuality, their sense of self retained a vital possessive aspect. Where participants fell short of these principles, the loss of a possessive self resulted in emotional pain and suffering. The validity of these findings were underscored by participants for whom the above moral principles – derived from the possessive nature of selfhood – were less important: married participants spoke about spousal relationships being deeply interdependent, and transcending possessive individual concerns. These findings are theoretical in their focus and may appear somewhat detached from the applied issues concerning social connectedness and health which were outlined in the initial Literature Review of this thesis. However, when allied to the insight offered in Chapter Seven (modes of value), the possessive aspects of selfhood and the ethical work undertaken to preserve this status describe the essential features of social resource exchange during multimorbidity. Consequently, this theoretical contribution speaks directly to nascent policies which seek

to utilise social resources in policies of health and social care. These issues will be outlined further in the sections which follow.

9.3 What does this study add?

This study contributes to knowledge in a number of ways. A primary contribution of this thesis is towards knowledge of an under-researched patient population, that is, people living with multimorbidity and the ways in which they give meaning to the experience of illness. In this regard, this study is also among the first to identify and question the biomedical assumptions which underpin the concept of multimorbidity: specifically, the focus upon disease rather than illness and the application of a biomedical model of concurrence.

A corollary of this has been a critique of the concept of illness prioritisation which has emerged in recent literature. Illness prioritisation accepts (implicitly) the biomedical assumption that the experience of multimorbidity consists of discrete or delimited conditions, with these conditions experienced or perceived by the individual as immediately concurrent. To reject illness prioritisation altogether may yet be hasty – people living with illness do understand particular conditions to be meaningfully different – however, this thesis sounds an important note of caution within a body of literature which has, to date, been resolutely in favour of illness prioritisation.

The critique of social capital and individualist social exchange afforded by this thesis is itself an important contribution to knowledge, given that social capital and social networks continue to be employed uncritically within health service and policy literature. However, the primary contribution of this thesis has been its treatment of social resources and in the conceptualisation of social resource exchange. This thesis has synthesised concepts and theory from wide-ranging perspectives not usually drawn upon within the sociology of health and illness. Specifically, this thesis contributes a pluralist reading of value, adapted

from Baudrillard (1981), and a conceptual model for how value and meaning are realised in supportive practice (*the interpretive economy meaning*).

Further, this thesis details the moral dilemmas and deliberations experienced during the receipt of support (a perspective which is often overlooked in favour of the perspective of care providers). In doing so, this thesis contributes to an understanding of support and the role of morality in shaping selfhood, individual dispositions, and actions in response to support. This thesis allies Foucault's writings on ethics (1985) with the concept of possessive individualism (Macpherson, 1962) to illustrate the ways in which people in receipt of support work to produce themselves as ethical individuals according to particular socio-political parameters (possessive individualism within a liberal democratic society). This is a novel contribution in both conceptual and empirical terms.

9.4 Policy implications

In recent years, multimorbidity has attracted increasing attention and support from academic research, and professionals from clinical practice, policy, and service design. In large part, this development is to be welcomed; services, therapies and clinical guidelines should reflect the empirical reality of multimorbidity rather than an outdated single-disease model of illness. Clearly, there is the potential for people living with multiple chronic conditions to face particular challenges in terms of navigating healthcare systems, self-managing multiple medications, and with regard to poorer physical and mental health outcomes (Fortin et al., 2007). However, as the concept of multimorbidity is adopted within academic and clinical practice, it is important to recognise the biomedical principles upon which it is premised. The chairman of the National Institute for Health and Care Excellence (NICE) has stated recently that 'We have to find a way of addressing the whole complex issue of multimorbidity ' adding, 'Finding a way to determine what looks good for a patient [with multimorbidity] is extraordinarily important' (Haslam, 2014). In this regard, policies addressing multimorbidity would benefit by affirming the distinction

between disease and illness, and should recognise multimorbidity as a concept which privileges a disease perspective rather than an illness perspective. Recognising multimorbidity as an illness experience akin to Paterson's (2001) shifting perspectives model – with its focus upon illness and wellness rather than disease – would likely lead to a more sensitive and effective treatment of multiple chronic conditions. Such insight might be delivered through a genuine engagement with the concept of person-centred care, and by recognising the potential for highly individualised needs within this patient population.

The literature review of this thesis identified social resources, social networks and community as salient themes in emerging health and social care policy. At a national level, 'capable communities' (DH, 2010) are promoted as a means towards re-orientating services and care provision from centrist to localised delivery – a policy which is representative of wider UK public services (Christie, 2011). This trend is apparent in the representation of health and social care users as 'active citizens' (DOH 2010) – a status which asserts the responsibility of communities towards their members rather than the rights of the individual – and social networks, neighbourhoods, and the public sphere more generally as 'capable communities' (DOH 2010) – communities are 'capable' insofar as they afford social resources. Emerging models of service organisation conceive of individuals and social groups in a similar way. An offshoot of community development theory (Kretzmann and McKnight 1996), asset-based models of health purport to make visible 'the skills, knowledge, connections and potential in a community', promoting 'capacity, connectedness and social capital' (McLean 2011: 2). In primary care, the concept of 'social prescribing' seeks to extend the tools available to general practitioners beyond those of biomedical intervention, to include the prescription of community based assets. Such assets may include voluntary work agencies, libraries, social or lunch groups, self-help groups, befriending organisations, hobby clubs, horticulture, sports clubs, nature conservation, book groups, art or dance classes, and the like (Brandling and House 2009: 454). The role of family and friends in the self-management of chronic illness

has also been recognised (Gallant, Spitze, and Prohaska 2007; Rosland and Piette, 2010; Vassilev et al. 2010), and calls have been made for patient's social networks to be recognised and incorporated into the self-care agenda (Rogers et al. 2011). Following this, the Theoretical Review chapter of this thesis identified and problematized several theoretical assumptions which underpin the turn towards social connectedness in health and social care policy. Current perspectives upon social resources, social networks and community routinely rely upon modes of social exchange which are, at their core, individualist. The concept of social capital continues to be the most visible example of this. This thesis has outlined the conceptual lineage of individualist exchange and in doing so, has highlighted inherent weaknesses; namely, an impoverished understanding of human agency, a reductive reading of social action (as instrumental action), and a general negligence of affective, social and cultural factors. The model of value and the critique of morality offered by this thesis are useful in considering how social resources might realistically be applied in health and social care policy. If policies such as those identified above are to be genuinely progressive in their incorporation of social resources, then vicissitudes of value and meaning must be recognised. Further, such policies must appreciate the moral dilemmas posed by social exchange. People in need of support and assistance often struggle to meet the principles of virtue and abstinence which are experienced during the receipt of support. As such, promoting social resources without heeding these issues may inadvertently contribute to suffering as the compulsion to maintain the possessive self becomes unattainable. One way of recognising these concerns, whilst reconciling them with emerging modes of service delivery, may be gleaned from the field of disability studies and the notion of independence according to an independent living philosophy. The independent living movement has been critical of independence in its possessive modes, and has contributed a model of independence premised upon interdependence with an emphasis on empowerment (Morris, 2004). The applied mechanism for such a philosophy is self-directed support (such as direct payments and personal budgets in social care) which enables the receipt of care and

support whilst simultaneously empowering the recipient of support. In this regard, the advent of personal health budgets is to be welcomed, as is the nascent integration of health and social care budgets and systems of support.

9.5 Future research

This thesis has highlighted a number of issues which would benefit from further research, and there are aspects of interest within this thesis which have not, as yet, been fully developed. The following section outlines these issues as topics for future research.

People living with multimorbidity remain an under-researched patient population. While this thesis has been somewhat critical of multimorbidity in conceptual terms, demographic factors and developments in healthcare determine that increasing numbers of people are, and will be, living with multiple chronic conditions. Accordingly, it is important that qualitative research continues to engage with the issue of multimorbidity and to shape debate concerning service design, therapies, and interventions aimed towards this patient population. Further, as biomedical and clinical research continues to advance understanding of the aetiology and pathophysiology of concurrent conditions, social research might seek to understand how aetiologically linked or commonly co-occurring chronic conditions are experienced in terms of health services, interactions with HCPs, and health promotion interventions. As healthcare systems transition from a focus on single diseases to ones which recognises the predominance of multimorbidity in ageing populations, new models of care may be informed usefully and effectively by insights from sociological theory and research.

Another focus of future research ought to be the experience of multimorbidity within distinct communities. This thesis has highlighted socio-cultural aspects of meaning, and has illustrated how these logics of meaning shape the receipt of support. However, this study recruited only participants of White British ethnic background and while social class varied within the sample, this study was relatively homogeneous in cultural terms. It is

conceivable that supportive practices may be interpreted differently within culturally distinct communities – LGBT communities as compared to South Asian communities, for example. As such, applying similar research questions, and considering the findings of this thesis in relation to different cultures and communities would be worthwhile.

In a similar vein, the forms of social resources considered in this study were largely – although not exclusively – examples of informal social support. As policies and services continue to incorporate social resources, the boundaries between formal and informal care are likely to become increasingly blurred. As such, considering the exchange of social resources in the spaces between informal and formal services is important. In this regard, services such as befriending and reading groups, or settings such as support groups and food banks warrant further research in relation to the illness experience and in terms of how they are to be usefully incorporated into primary care. Further, the role of third sector organisations (who are increasingly delivering services formerly undertaken by the public sector) should be addressed. Such models of service provision represent an important avenue of research in that these services are neither purely informal (often requiring some form of payment), nor formal, but represent new forms of hybridised service.

Another issue for future research concerns the divide between health and social care. There have been, in recent decades, widespread calls to integrate health and social care systems in the care of people living with complex and long-term conditions. Understanding the experience of older people living with multimorbidity would benefit from similar integration between health and social care research. The distinction between health and social care research risks duplication of knowledge and may result in the promotion of solutions which reinforce the divide between health and social care. Future research into the experience of multimorbidity (a patient population that are high users of both health and social care services) would benefit from a ‘whole systems’ approach which draws upon knowledge and expertise from health and social care researchers – as well as those

with expertise in policy and service organisation – to deliver sensitive and sophisticated solutions to the challenges faced by people living with multimorbidity.

In terms of sociological research generally, issues of support, co-operation and social networks would benefit from incorporating gift-exchange literature into the conceptual repertoire. Baudrillard's early work – which bridges anthropology, semiotics, and political economy – may be particularly useful in this direction. Future research might seek to explore the possibilities and limits of these theoretical issues in applied terms.

9.6 Conclusion

The concept of multimorbidity – taken to mean the 'co-existence of two or more long-term conditions in an individual' (Mercer et al., 2009) – does not conceptualise adequately the lay experience of illness. Lay individuals often do not consider their health in terms of delimited conditions, nor as immediately concurrent conditions. Rather, experiences of multimorbidity vary enormously and are made sense of according to intersecting corporal, social, cultural and biographical logics.

Social resource exchanges are complex social practices and cannot be understood through individualist, rationalist, or instrumental perspectives. Rather, understanding social resource exchange requires an appreciation of the various coalescing logics of value which inform the meaning of supportive acts. Morality is of central concern in these processes. Identifying the moral principles of exchange and recognising these principles as constituted by a particular (socio-politically informed) mode of individualism is essential to understanding social resource exchange.

These findings are of relevance to clinical practice, the design of interventions, and also at the level of health and social care policy. Acknowledging the findings of this thesis may, in some small fashion, contribute to an experience of illness wherein suffering is less pronounced.

References

- Abbott, S., & Freeth, D. (2008). Social capital and health starting to make sense of the role of generalized trust and reciprocity. *Journal of Health Psychology, 13*(7), 874-883.
- Alpass, F., Towers, A., Stephens, C., Fitzgerald, E., Stevenson, B., & Davey, J. (2007). Independence, Well-being, and Social Participation in an Aging Population. *Annals of the New York Academy of Sciences, 1114*(1), 241-250.
- Alvesson, M., & Skoldberg, K. (2000). *Reflexive methodology*. London: Sage.
- Antonucci, T. C. (2009). Convoy model of social relations. In H. Reis. & S. Sprecher. (Eds.). *Encyclopaedia of human relationships*. (pp. 327-329). Thousand Oaks, California: Sage.
- Antonucci, T. C., & Akiyama, H. (1987). Social networks in adult life and a preliminary examination of the convoy model. *Journal of Gerontology, 42*(5), 519-527.
- Antonucci, T. C., & Akiyama, H. (1991). Convoys of social support: Generational issues. *Marriage & Family Review, 16*(1-2), 103-124.
- Antonucci, T. C., & Akiyama, H. (1995). Convoys of social relations: Family and friendships within a life span context.
- Arber, S., & Cooper, H. (1999). Gender differences in health in later life: the new paradox?. *Social science & medicine, 48*(1), 61-76.

Archer, M. (2013). The 'logic of the gift': can it find a place within normal economic activity? *Second Spring: a journal of faith and culture*. Retrieved February 1st 2013 from http://www.secondspring.co.uk/uploads/articles_19_953760526.pdf

Archer, M. S. (1995). *Realist social theory: The morphogenetic approach*. Cambridge: Cambridge university press.

Armstrong, D. (2009). Origins of the Problem of Health-related Behaviours: A Genealogical Study. *Social studies of science*, 39(6), 909-926.

Baltes, M. M., & Carstensen, L. L. (1996). The process of successful ageing. *Ageing and society*, 16(4), 397-422.

Barnes, J. A. (2002). Norwegian Island Parish. *Social Networks: Critical Concepts in Sociology*, 2, 311.

Barrera Jr, M. (1986). Distinctions between social support concepts, measures, and models. *American journal of community psychology*, 14(4), 413-445.

Barthes, R. (1972). *Mythologies*. London: Macmillan.

Baudrillard, J. (1981). *For a Critique of the Political Economy of the Sign*. USA: Telos Press Publishing.

Bayliss, E. A., Bayliss, M. S., Ware, J. E., & Steiner, J. F. (2004). Predicting declines in physical function in persons with multiple chronic medical conditions: what we can learn from the medical problem list. *Health and Quality of Life Outcomes*, 2(1), 47.

- Bayliss, E. A., Steiner, J. F., Fernald, D. H., Crane, L. A., & Main, D. S. (2003). Descriptions of barriers to self-care by persons with comorbid chronic diseases. *Annals of Family Medicine*, 1(1), 15-21.
- Bazeley, P., & Richards, L. (2000). *The NVivo qualitative project book*. London: Sage.
- Becker, G. S. (1976). *The economic approach to human behaviour*. Chicago: University of Chicago Press.
- Becker, H. S. (1982). *Art Worlds*. London: University of California Press.
- Bergeron, E., Lavoie, A., Moore, L., Clas, D., & Rossignol, M. (2005). Comorbidity and age are both independent predictors of length of hospitalization in trauma patients. *Canadian journal of surgery*, 48(5), 361.
- Berkman, L. F., & Syme, S. L. (1979). Social networks, host resistance, and mortality: a nine-year follow-up study of Alameda County residents. *American journal of Epidemiology*, 109(2), 186-204.
- Blaikie, N. (2000). *Designing social research*. Cambridge: Polity Press.
- Blau, P. M. (1964). *Exchange and power in social life*. New York: John Wiley & Sons Ltd.
- Blaxter, M. (2004). *Health: Key concepts*. Cambridge: Polity Press.
- Blaxter, M., & Poland, F. (2002). Moving beyond the survey in exploring social capital. *Social capital for health*, 87.

Blickem, C., Blakeman, T., Kennedy, A., Bower, P., Reeves, D., Gardner, C., ... & Rogers, A. (2013). The clinical and cost-effectiveness of the Bringing Information and Guided Help Together (BRIGHT) intervention for the self-management support of people with stage 3 chronic kidney disease in primary care: study protocol for a randomized controlled trial. *Trials*, 14(1), 28-28.

Bott, E. (1957). *Family and social network: roles, norms, and external relationships in ordinary urban families*. London: Tavistock Publications.

Bourdieu, P. (1977). *Outline of a Theory of Practice*. Cambridge: Cambridge university press.

Bourdieu, P. (1986). The forms of capital. In: Richardson, JG (ed.) *Handbook of theory and research for the sociology of education*. London: Greenwood Press.

Bourdieu, P. (1990). *The logic of practice*. Cambridge: Polity Press.

Bourdieu, P. (1996). On the family as a realized social category. *Theory, Culture & society*, 13(3), 19-26.

Bourdieu, P., & Wacquant, L. J. (Eds.). (1992). *An invitation to reflexive sociology*. Chicago: University of Chicago Press.

Bowling, A. (2001). *Research methods in health*. Maidenhead: Open University Press.

Bowling, A., & Dieppe, P. (2005). What is successful ageing and who should define it?. *BMJ: British Medical Journal*, 331(7531),1548.

Boyd, C. M., Darer, J., Boulton, C., Fried, L. P., Boulton, L., & Wu, A. W. (2005). Clinical practice guidelines and quality of care for older patients with multiple comorbid diseases: implications for pay for performance. *Jama*, 294(6), 716-724.

Brandling, J., & House, W. (2009). Social prescribing in general practice: adding meaning to medicine. *British Journal of General Practice*, 59(563), 454-456.

Breheny, M., & Stephens, C. (2009). 'I sort of pay back in my own little way': managing independence and social connectedness through reciprocity. *Ageing and Society*, 29(8), 1295-1313.

Breheny, M., & Stephens, C. (2012). Negotiating a moral identity in the context of later life care. *Journal of aging studies*, 26(4), 438-447.

Brooks, F., & Kendall, S. (2013). Making sense of assets: what can an assets based approach offer public health? *Critical Public Health*, 23(2), 127-130.

Bryman, A. (1988). Quantity and quality in social research. New York: Unwin Hyman Ltd.

Bryman, A. (2008). *Social research methods*. Oxford university press.

Burns, H. (2011). Annual report to the chief medical officer: health in Scotland 2010 assets for health. Retrieved 1st September 2012 from:

<http://www.scotland.gov.uk/Publications/2011/12/14120931/0>

Bury, M. (1991). The sociology of chronic illness: a review of research and prospects. *Sociology of Health & Illness*, 13(4), 451-468.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, 4(2), 167-182.

Bury, M., & Holme, A. (1991). *Life after ninety* Routledge, London, England and New York, NY.

Cabinet Office. (2011). *Open public services: white paper* (Vol. 8145).

Carrier, J. (1991). Gifts, commodities, and social relations: A Maussian view of exchange. In *Sociological forum* (Vol. 6, No. 1, pp. 119-136).

Charles, N. and Walters, V. (1998) Age and gender in women's accounts of their Health: Interviews with women in South Wales, *Sociology of Health and Illness*, 20, 331-50.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of health & illness*, 5(2), 168-195.

Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. London: Rutgers University Press.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage.

Charmaz, K. (2008). Constructionism and the grounded theory method. In Holstein, J., and Gubrium, J. *Handbook of constructionist research*. London: The Guilford Press.

- Cheraghi-Sohi, S., Bower, P., Kennedy, A., Morden, A., Rogers, A., Richardson, J., ... & Ong, B. N. (2013). Patient priorities in osteoarthritis and comorbid conditions: a secondary analysis of qualitative data. *Arthritis care & research*, 65(6), 920-927.
- Christie, C. (2011). Commission on the future delivery of public services. Scotland: APS Group.
- Clarke, L. H., & Bennett, E. V. (2013). Constructing the moral body: Self-care among older adults with multiple chronic conditions. *Health*, 17(3), 211-228.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological bulletin*, 98(2), 310.
- Cohn, S. (2014). From health behaviours to health practices: an introduction. *Sociology of health & illness*, 36(2), 157-162.
- Coleman, J. (1988). Social Capital in the Creation of Human Capital. *American Journal of Sociology*, 94, S95-S12.
- Coleman, J. S. (1990). *Foundations of social theory*. London: Harvard University Press
- Cook, K. S., & Whitmeyer, J. M. (1992). Two approaches to social structure: Exchange theory and network analysis. *Annual Review of Sociology*, 109-127.
- Corbin, J. M., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. London: Jossey-Bass.
- Coulter, A. (2009). Engaging communities for health improvement: a scoping study for the Health Foundation. London: Health Foundation.

Cronin, A., & King, A. Only connect? Older lesbian, gay and bisexual (LGB) adults and social capital. *Ageing and Society*, 1-22.

Crossley, N. (2010). *Towards relational sociology*. London: Routledge.

De Certeau, M. (1998). *The Practice of Everyday Life*. New York: University of Minnesota Press.

Department of Health. (2010). A vision for adult social care: Capable communities and active citizens.

Deroose, K. P., & Varda, D. M. (2009). Social Capital and Health Care Access A Systematic Review. *Medical Care Research and Review*, 66(3), 272-306

Dolan, A. (2007). That's just the cesspool where they dump all the trash: exploring working class men's perceptions and experiences of social capital and health. *Health*, 11(4), 475-495.

Drentea, P., & Moren-Cross, J. L. (2005). Social capital and social support on the web: the case of an internet mother site. *Sociology of health & illness*, 27(7), 920-943.

Durkheim, E. (1961). *Moral Education*. New York: The Free Press.

Durkheim, E. (1999). *Suicide: A Study in Sociology*. London: Routledge.

Ekeh, P. (1974). *Social exchange theory: The two traditions*. Cambridge: Harvard University Press.

Elias, N. (2000). *The civilizing process*. London: Wiley-Blackwell.

Elliott, R. A., Ross-Degnan, D., Adams, A. S., Safran, D. G., & Soumerai, S. B. (2007). Strategies for coping in a complex world: Adherence behavior among older adults with chronic illness. *JGIM: Journal of General Internal Medicine*, 22(6), 805-810.

Feinstein, A. R. (1970). The pre-therapeutic classification of co-morbidity in chronic disease. *Journal of Chronic Diseases*, 23(7), 455-468.

Fine, B. (2008). Social capital versus social history. *Social History*, 33(4), 442-467.

Fine, B. (2010). *Theories of social capital: Researchers behaving badly*. Pluto.

Fine, B., & Milonakis, D. (2009). *From economics imperialism to freakonomics: The shifting boundaries between economics and other social sciences*. London: Routledge.

Fiori, K. L., Consedine, N. S., & Magai, C. (2008). Ethnic differences in patterns of social exchange among older adults: the role of resource context. *Ageing and Society*, 28(4), 495-524.

Fishman, P., Von Korff, M., Lozano, P., & Hecht, J. (1997). Chronic care costs in managed care. *Health Affairs*, 16(3), 239-247.

Foot, J., & Hopkins, T. (2010). *A glass half-full: how an asset approach can improve community health and well-being*. London: Improvement and Development Agency.

Foot, J. (2012). What makes us healthy? *The asset based approach in practice: evidence, action, evaluation*. Retrieved 1st May 2013 from

<http://www.assetbasedconsulting.co.uk/uploads/publications/WMUH.pdf>

Fortin, M., Bravo, G., Hudon, C., Lapointe, L., Dubois, M. F., & Almirall, J. (2006). Psychological distress and multimorbidity in primary care. *The Annals of Family Medicine*, 4(5), 417-422.

Fortin, M., Bravo, G., Hudon, C., Vanasse, A., & Lapointe, L. (2005). Prevalence of multimorbidity among adults seen in family practice. *The Annals of Family Medicine*, 3(3), 223-228.

Fortin, M., Dionne, J., Pinho, G., Gignac, J., Almirall, J., & Lapointe, L. (2006). Randomized controlled trials: do they have external validity for patients with multiple comorbidities?. *The Annals of Family Medicine*, 4(2), 104-108.

Fortin, M., Lapointe, L., Hudon, C., Vanasse, A., Ntetu, A. L., & Maltais, D. (2004). Multimorbidity and quality of life in primary care: a systematic review. *Health and Quality of life Outcomes*, 2(1), 51.

Fortin, M., Soubhi, H., Hudon, C., Bayliss, E. A., & van den Akker, M. (2007). Multimorbidity's many challenges. *BMJ: British Medical Journal*, 334(7602), 1016.

Fortin, M., Stewart, M., Poitras, M. E., Almirall, J., & Maddocks, H. (2012). A systematic review of prevalence studies on multimorbidity: toward a more uniform methodology. *The Annals of Family Medicine*, 10(2), 142-151.

Foucault, M. (1985). *The history of sexuality: the use of pleasure*. London: Penguin.

Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. London: University of Chicago Press.

Friedli, L. (2013). 'What we've tried, hasn't worked': the politics of assets based public health 1. *Critical Public Health*, 23(2), 131-145.

Friedman, B., Jiang, H. J., Elixhauser, A., & Segal, A. (2006). Hospital inpatient costs for adults with multiple chronic conditions. *Medical care research and review*, 63(3), 327-346.

Frohlich, D. O. (2014). The social support model for people with chronic health conditions: A proposal for future research. *Social Theory & Health*, 12(2), 218-234.

Fu, Y. C. (2005). Measuring personal networks with daily contacts: a single-item survey question and the contact diary. *Social Networks*, 27(3), 169-186.

Fu, Y. C. (2007). Contact Diaries Building Archives of Actual and Comprehensive Personal Networks. *Field Methods*, 19(2), 194-217.

Gadamer, H. G. (1975). *Truth and Method*. London: Sheed and Ward.

Gallant, M. P., Spitze, G. D., & Prohaska, T. R. (2007). Help or hindrance? How family and friends influence chronic illness self-management among older adults. *Research on Aging*, 29(5), 375-409.

Gallant, M. P., Spitze, G., & Grove, J. G. (2010). Chronic illness self-care and the family lives of older adults: A synthetic review across four ethnic groups. *Journal of cross-cultural gerontology*, 25(1), 21-43.

Garfinkel, H. (1986). *Studies in Ethnomethodology*. London: Polity Press.

Geertz, C. (1973). *The interpretation of cultures: Selected essays*. New York: Fontana Press.

Gibbs, G. R. (2007). *Analysing qualitative data*. London: Sage.

Giddens, A. (1984). *The constitution of society: Outline of the theory of structuration*. London: John Wiley & Sons Ltd.

Giddens, A. (2000). *The third way: The renewal of social democracy*. Cambridge: Polity Press.

Gijzen, R., Hoeymans, N., Schellevis, F. G., Ruwaard, D., Satariano, W. A., & van den Bos, G. A. (2001). Causes and consequences of comorbidity: a review. *Journal of clinical epidemiology*, 54(7), 661-674.

Gilleard, C., & Higgs, P. (2013). *Ageing, corporeality and embodiment*. London: Anthem Press.

Glynn, L. G., Valderas, J. M., Healy, P., Burke, E., Newell, J., Gillespie, P., & Murphy, A. W. (2011). The prevalence of multimorbidity in primary care and its effect on health care utilization and cost. *Family practice*, 28(5), 516-523.

Goodman, R. A., Posner, S. F., Huang, E. S., Parekh, A. K., & Koh, H. K. (2013). Defining and Measuring Chronic Conditions: Imperatives for Research, Policy, Program, and Practice. *Preventing Chronic Disease*, 10. doi: <http://dx.doi.org/10.5888/pcd10.120239>

Graeber, D. (2001). *Toward an anthropological theory of value: the false coin of our own dreams*. London: Palgrave Macmillan.

Granovetter, M. (1973). The strength of weak ties. *American journal of sociology*, 78(6), 1360-1380.

Granovetter, M. (1985). Economic action and social structure: the problem of embeddedness. *American journal of sociology*, 91(3), 481-510.

Granovetter, M. (1990). The myth of social network analysis as a special method in the social sciences. *Connections*, 13(1-2), 13-16.

Green, J., & Thorogood, N. (2014). *Qualitative methods for health research*. London: Sage.

Gunn, J. M., Ayton, D. R., Densley, K., Pallant, J. F., Chondros, P., Herrman, H. E., & Dowrick, C. F. (2012). The association between chronic illness, multimorbidity and depressive symptoms in an Australian primary care cohort. *Social psychiatry and psychiatric epidemiology*, 47(2), 175-184.

Guthrie, B., Payne, K., Alderson, P., McMurdo, M. E., & Mercer, S. W. (2012). Adapting clinical guidelines to take account of multimorbidity. *British Medical Journal*, 345(oct04), e6341-e6341

Guyatt, G. (1997). Insights and limitations from health-related quality-of-life research. *Journal of General Internal Medicine*, 12(11), 720-721.

Haslam, D. (2014) *Nice to move to multimorbidity guidance, chief says*. Retrieved 1st May 2014 from <http://www.pulsetoday.co.uk/clinical/therapy-areas/prescribing/nice-to-move-to-multimorbidity-guidance-chief-says/20006558.article#.U5SMaHJdWSo>

Hodgkin, S. (2008). Telling It All A Story of Women's Social Capital Using a Mixed Methods Approach. *Journal of Mixed Methods Research*, 2(4), 296-316.

Homans, G. C. (1950). *The Human Group*. New York: Harcourt, Brace & World.

Homans, G. C. (1974). *Social behaviour: Its elementary forms*. New York: Harcourt, Brace & World.

Horne, M., Khan, H., & Corrigan, P. (2013). *People Powered Health: Health for People, by People and with People*. London: NESTA.

Houdt, F., & Schinkel, W. (2013). Crime, citizenship and community: neoliberal communitarian images of governmentality. *The Sociological Review*, 62(1), 47-67.

House, J. S. (1981). *Work stress and social support*. London: Addison-Wesley Publishing.

House, J. S., Kahn, R. L., McLeod, J. D., & Williams, D. (1985). Measures and concepts of social support. In Cohen, S. E., & Syme, S. (Eds.). *Social support and health*. New York: Academic Press.

House, J. S., Landis, K. R., & Umberson, D. (1988). Social relationships and health. *Science*, 241(4865), 540-545.

House, J. S., Robbins, C., & Metzner, H. L. (1982). The association of social relationships and activities with mortality: prospective evidence from the Tecumseh Community Health Study. *American journal of epidemiology*, 116(1), 123-140.

Hughes, L. D., McMurdo, M. E., & Guthrie, B. (2013). Guidelines for people not for diseases: the challenges of applying UK clinical guidelines to people with multimorbidity. *Age and ageing*, 42(1), 62-69.

Johnson, J. M. (2002). In-depth interviewing. In Gubrium, J. F., & Holstein, J. A. (Eds.). *Handbook of interview research: Context and method*. London: Sage.

Johnson, T. Dandeker, C. Ashworth, C. (1984). The structure of social theory. Basingstoke: Macmillan.

Kadam, U. (2012). Redesigning the general practice consultation to improve care for patients with multimorbidity. *BMJ: British Medical Journal*, doi: 345:e6202

Kadam, U. T., & Croft, P. R. (2007). Clinical comorbidity in osteoarthritis: associations with physical function in older patients in family practice. *The Journal of rheumatology*, 34(9), 1899-1904.

Kaplan, S., Talbot, J. F., & Kaplan, R. (1988). Coping with daily hassles: The impact of nearby nature on the work environment. *Saint Paul (MN): USDA Forest Service, North Central Forest Experiment Station, Urban Forestry Unit Cooperative*.

Kawachi, I., Subramanian, S. V., & Kim, D. (Eds.). (2008). *Social capital and health*. Springer New York.

Kendall, E., & Rogers, A. (2007). Extinguishing the social?: state sponsored self-care policy and the Chronic Disease Self-management Programme. *Disability & Society*, 22(2), 129-143.

Kendall, E., Ehrlich, C., Sunderland, N., Muenchberger, H., & Rushton, C. (2011). Self-managing versus self-management: reinvigorating the socio-political dimensions of self-management. *Chronic Illness*, 7(1), 87-98.

Kerr, E. A., Heisler, M., Krein, S. L., Kabeto, M., Langa, K. M., Weir, D., & Piette, J. D. (2007). Beyond comorbidity counts: How do comorbidity type and severity influence diabetes patients' treatment priorities and self-management? *JGIM: Journal of General Internal Medicine*, 22(12), 1635-1640.

Kisby, B. (2010). The Big Society: power to the people?. *The Political Quarterly*, 81(4), 484-491.

Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. Basic Books.

Koetsenruijter, J., van Lieshout, J., Vassilev, I., Portillo, M. C., Serrano, M., Knutsen, I., . . . Wensing, M. (2014). Social support systems as determinants of self-management and quality of life of people with diabetes across europe: Study protocol for an observational study. *Health and Quality of Life Outcomes*, 12(1), 29-29. doi:10.1186/1477-7525-12-29

Kretzmann, J., & McKnight, J. P. (1996). Assets-based community development. *National Civic Review*, 85(4), 23-29.

Kvale, S., & Brinkmann, S. (2009). *Interviews: Learning the craft of qualitative research interviewing*. London: Sage.

Landi, F., Liperoti, R., Russo, A., Capoluongo, E., Barillaro, C., Pahor, M., ... & Onder, G. (2010). Disability, more than multimorbidity, was predictive of mortality among older persons aged 80 years and older. *Journal of clinical epidemiology*, 63(7), 752-759.

Lawson, K. D., Mercer, S. W., Wyke, S., Grieve, E., Guthrie, B., Watt, G. C., & Fenwick, E. A. L. (2013). Double trouble: the impact of multimorbidity and deprivation on preference-weighted health related quality of life a cross sectional analysis of the Scottish Health Survey. *Int J Equity Health*, 12(1), 67.

Lévi-Strauss, C. (1969). *The elementary structures of kinship*. London: Beacon Press.

Levitas, R. (2012). The Just's Umbrella: Austerity and the Big Society in Coalition policy and beyond. *Critical social policy*, 32(3), 320-342.

Lin, N. (1982). *Social resources and instrumental action*. In Marsden, P. V., and Lin, N. (Eds.). (1982). *Social structure and networks analysis*. Beverley Hills: Sage.

Lin, N. (2001). *Social capital: A theory of social structure and action*. Cambridge Cambridge University Press.

Lin, N., & Dean, A. (1984). Social support and depression. *Social Psychiatry and Psychiatric Epidemiology*, 19(2), 83-91.

Lin, N., & Ensel, W. M. (1989). Life stress and health: stressors and resources. *American Sociological Review*. 54(3), 382-399.

Lin, N., Dayton, P. W., & Greenwald, P. (1978). Analyzing the instrumental use of relations in the context of social structure. *Sociological Methods & Research*, 7(2), 149-166.

Lin, N., Vaughn, J. C., & Ensel, W. M. (1981). Social resources and occupational status attainment. *Social forces*, 59(4), 1163-1181.

Lindsay, S. (2009). Prioritizing illness: Lessons in self-managing multiple chronic diseases. *Canadian Journal of Sociology*, 34(4), 983-1002.

Löffler, C., Kaduszkiewicz, H., Stolzenbach, C. O., Streich, W., Fuchs, A., van den Bussche, H., ... & Altiner, A. (2012). Coping with multimorbidity in old age—a qualitative study. *BMC family practice*, 13(1), 1-8.

Loomis, M. E., & Conco, D. (1991). Patients' perceptions of health, chronic illness, and nursing diagnoses. *International Journal of Nursing Terminologies and Classifications*, 2(4), 162-170.

MacIntyre, A. C. (1988). *Whose justice? Which rationality?* London: Duckworth.

Macintyre, S., Hunt, K., & Sweeting, H. (1996). Gender differences in health: are things really as simple as they seem?. *Social science & medicine*, 42(4), 617-624.

Macleod, U., Mitchell, E., Black, M., & Spence, G. (2004). Comorbidity and socioeconomic deprivation: An observational study of the prevalence of comorbidity in general practice. *The European Journal of General Practice*, 10(1), 24-26.

Macpherson, C. B. (1962). *The political theory of possessive individualism*. Oxford: Clarendon Press.

Marengoni, A., Angleman, S., Melis, R., Mangialasche, F., Karp, A., Garmen, A., ... & Fratiglioni, L. (2011). Aging with multimorbidity: a systematic review of the literature. *Ageing research reviews*, 10(4), 430-439.

Marmot, M., & Wilkinson, R. (Eds.). (2005). *Social determinants of health*. Oxford: Oxford University Press.

Marsden, P. V., & Lin, N. (1982). *Social structure and networks analysis* (No. 57). Beverley Hills: Sage.

Martinson, M., & Berridge, C. (2014). Successful Aging and Its Discontents: A Systematic Review of the Social Gerontology Literature. *The Gerontologist*, doi:10.1093/geront/gnu037

Marx, K. (1859). *A contribution to the critique of political economy*. Retrieved 14th February 2012 from http://www.marxists.org/archive/marx/works/download/Marx_Contribution_to_the_Critique_of_Political_Economy.pdf

Marx, K. (1976). *Value: Studies* (A. Dragstedt, Trans.). London: New Park Publications.

Mauss, M. (2011). *The gift: Forms and functions of exchange in archaic societies*. London: Routledge.

May, C., Montori, V., & Mair, F. (2009). We need minimally disruptive medicine. *BMJ. British medical journal*, 339(7719), 485-487.

McClean, S., & Shaw, A. (2005). From schism to continuum? The problematic relationship between expert and lay knowledge—an exploratory conceptual synthesis of two qualitative studies. *Qualitative Health Research*, 15(6), 729-749.

Mc Sharry, J., Bishop, F. L., Moss-Morris, R., & Kendrick, T. (2013). 'The chicken and egg thing': Cognitive representations and self-management of multimorbidity in people with diabetes and depression. *Psychology & health*, 28(1), 103-119.

McDaid, O., Hanly, M. J., Richardson, K., Kee, F., Kenny, R. A., & Savva, G. M. (2012). The effect of multiple chronic conditions on self-rated health, disability and quality of life among the older populations of Northern Ireland and the Republic of Ireland: a comparison of two nationally representative cross-sectional surveys. *BMJ open*, 3(6), 52-61.

McKnight, J. L., & Kretzmann, J. L. (1996). *Mapping community capacity*. Institute for Policy Research, Northwestern University.

McLean, J. (2011). Asset based approaches for health improvement: redressing the balance. *UK: Glasgow Centre for Population Health*.

Menotti, A., Mulder, I., Nissinen, A., Giampaoli, S., Feskens, E. J., & Kromhout, D. (2001). Prevalence of morbidity and multimorbidity in elderly male populations and their impact on 10-year all-cause mortality: The FINE study. *Journal of Clinical Epidemiology*, 54(7), 680-686.

- Mercer, S. W., Gunn, J., Bower, P., Wyke, S., & Guthrie, B. (2012). Managing patients with mental and physical multimorbidity. *BMJ*, 345, doi: e5559-e5559.
- Mercer, S. W., Smith, S. M., Wyke, S., O'Dowd, T., & Watt, G. C. (2009). Multimorbidity in primary care: developing the research agenda. *Family practice*, 26(2), 79-80.
- Moore, S., Haines, V., Hawe, P., & Shiell, A. (2006). Lost in translation: A genealogy of the "social capital" concept in public health. *Journal of Epidemiology & Community Health*, 60(8), 729-734.
- Moore, S., Shiell, A., Hawe, P., & Haines, V. A. (2005). Public health matters. the privileging of communitarian ideas: Citation practices and the translation of social capital into public health research. *American Journal of Public Health*, 95(8), 1330-1337.
- Morden, A., Jinks, C., & Bie, N. O. (2011). Lay models of self-management: how do people manage knee osteoarthritis in context?. *Chronic illness*, 7(3), 185.
- Moren-Cross, J. L., & Lin, N. (2006). Social networks and health. *Handbook of aging and the social sciences, volume 6*. London: Academic Press.
- Morris, J. (2004). Independent living and community care: a disempowering framework. *Disability & Society*, 19(5), 427-442.
- Morris, R. L., Sanders, C., Kennedy, A. P., & Rogers, A. (2011). Shifting priorities in multimorbidity: a longitudinal qualitative study of patient's prioritization of multiple conditions. *Chronic Illness*, 7(2), 147-161.
- Murdoch, I. (1962). *The bell*. London: Penguin.

Nagl, A., Witte, J., Hodek, J. M., & Greiner, W. (2012). Relationship between multimorbidity and direct healthcare costs in an advanced elderly population. *Zeitschrift für Gerontologie und Geriatrie*, 45(2), 146-154.

National Endowment for Science, Technology and the Arts [NESTA]. (2013). The business case for people powered health. Retrieved 1st March 2013 from http://www.nesta.org.uk/sites/default/files/the_business_case_for_people_powered_health.pdf

Nettleton, S. (1995). *The sociology of health and illness*. Cambridge: Blackwell Publishing Ltd.

National Institute for Health and Clinical Excellence [NICE]. (2012). NICE should consider multimorbidity in guidelines. *NICE online*. Retrieved 1st November 2012, from <http://www.nice.org.uk/newsroom/news/NICEShouldConsiderMultimorbidityInGuidelines.jsp>

Neusner, J., & Chilton, B. (2008). *The Golden Rule: Analytical Perspectives*. London: Continuum International Publishing Group.

Ong, B. N., & Jinks, C. (2006). Walking like John Wayne': open-format diaries of people with knee pain and disability. *Chronic illness*, 2(1), 21-26.

Ong, B. N., & Jinks, C. (2009). Reflections on becoming a person with musculoskeletal pain: A patient diary. *Social Theory & Health*, 7(2), 100-116.

Ong, B. N., Jinks, C., & Morden, A. (2011). The hard work of self-management: Living with chronic knee pain. *International journal of qualitative studies on health and well-being*, 6(3).

Ong, B. N., Richardson, J. C., Porter, T., & Grime, J. (2014). Exploring the relationship between multi-morbidity, resilience and social connectedness across the lifecourse. *Health*, 18(3), 302-318.

Ong, B. N., Rogers, A., Kennedy, A., Bower, P., Sanders, T., Morden, A., ... & Stevenson, F. (2014). Behaviour change and social blinkers? The role of sociology in trials of self-management behaviour in chronic conditions. *Sociology of health & illness*, 36(2), 226-238.

Orth-Gomér, K., Undén, A. L., & Edwards, M. E. (1987). Social isolation and mortality in ischemic heart disease. A 10-year follow-up study of 150 middle-aged men. *Acta medica Scandinavica*, 224(3), 205-215.

Ortner, S. B. (1984). Theory in anthropology since the sixties. *Comparative Studies in Society and History*, 26(1), 126-166.

Ortner, S. B. (2005). Subjectivity and cultural critique. *Anthropological Theory*, 5(1), 31-52.

Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of nursing scholarship*, 33(1), 21-26.

Patton, M. Q. (1990). *Qualitative evaluation and research methods*. London: SAGE.

- Payne, R. A., Abel, G. A., Guthrie, B., & Mercer, S. W. (2013). The effect of physical multimorbidity, mental health conditions and socioeconomic deprivation on unplanned admissions to hospital: a retrospective cohort study. *Canadian Medical Association Journal*, 185(5), doi: 10.1503/cmaj.121349
- Phillipson, C. (Ed.). (2001). *The family and community life of older people: Social networks and social support in three urban areas*. London: Routledge.
- Pickard, S., & Rogers, A. (2012). Knowing as practice: Self-care in the case of chronic multi-morbidities. *Social Theory & Health*, 10(2), 101-120.
- Portes, A. (2000). The two meanings of social capital. In *Sociological forum*, 15(1), 1-12.
- Pound, P., Gompertz, P., & Ebrahim, S. (1998). Illness in the context of older age: The case of stroke. *Sociology of Health & Illness*, 20(4), 489-506.
- Prabhakar, R. (2013). Asset-based welfare: Financialization or financial inclusion? *Critical Social Policy*, 33(4), 658-678.
- Putnam, R. D. (2000). *Bowling alone: The collapse and revival of American community*. London: Simon and Schuster Paperbacks.
- Ramage-Morin, P. L. (2009). Medication use among senior Canadians. *Health Rep*, 20(1), 37-44.
- Rier, D. A. (2007). Internet social support groups as moral agents: the ethical dynamics of HIV+ status disclosure. *Sociology of health & illness*, 29(7), 1043-1058.

Riessman, C. K. (Ed.). (1993). *Narrative analysis*. London: Sage.

Rijken, M., van Kerkhof, M., Dekker, J., & Schellevis, F. G. (2005). Comorbidity of chronic diseases. *Quality of Life Research*, 14(1), 45-55.

Rogers, A., Vassilev, I., Sanders, C., Kirk, S., Chew-Graham, C., Kennedy, A., . . .

Richardson, G. (2011). Social networks, work and network-based resources for the management of long-term conditions: A framework and study protocol for developing self-care support. *Implementation Science*, 6(1), 56-62.

Rogers, A., Brooks, H., Vassilev, I., Kennedy, A., Blickem, C., & Reeves, D. (2014). Why less may be more: a mixed methods study of the work and relatedness of 'weak ties' in supporting long-term condition self-management. *Implement Sci*, 9, 19.

Rorty, R. (1978). Philosophy as a kind of writing: An essay on Derrida. *New Literary History*, 141-160.

Rosland, A. M., & Piette, J. D. (2010). Emerging models for mobilizing family support for chronic disease management: a structured review. *Chronic Illness*, 6(1), 7-21.

Rozanova, J. (2010). Discourse of successful aging in The Globe & Mail: Insights from critical gerontology. *Journal of Aging Studies*, 24(4), 213-222.

Sage, D. (2012). A challenge to liberalism? The communitarianism of the Big Society and Blue Labour. *Critical social policy*, 32(3), 365-382.

Sahlins, M. (1985). *Islands of history*. London: University of Chicago Press.

Salisbury, C., Johnson, L., Purdy, S., Valderas, J. M., & Montgomery, A. A. (2011). Epidemiology and impact of multimorbidity in primary care: a retrospective cohort study. *British Journal of General Practice*, 61(582), 12-21.

Sanders, C., Donovan, J., & Dieppe, P. (2002). The significance and consequences of having painful and disabled joints in older age: Co-existing accounts of normal and disrupted biographies. *Sociology of Health & Illness*, 24(2), 227-253.

Sanderson, T., Calnan, M., Morris, M., Richards, P., & Hewlett, S. (2011). Shifting normalities: Interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis. *Sociology of health & illness*, 33(4), 618-633.

Saussure, F.D. (1966). *Course in General Linguistics* (W. Bakins, Trans.). New York: McGraw Hill.

Sayer, A. (2011). Why things matter to people. *Social Science, Values, and Ethical Life*. Cambridge: Cambridge University Press.

Schneider, K. M., O'Donnell, B. E., & Dean, D. (2009). Prevalence of multiple chronic conditions in the United States' Medicare population. *Health Qual Life Outcomes*, 7(82), 82.

Schoenbach, V. J., Kaplan, B. H., Fredman, L., & Kleinbaum, D. G. (1986). Social ties and mortality in Evans County, Georgia. *American Journal of Epidemiology*, 123(4), 577-591.

Schoenberg, N. E., Leach, C., & Edwards, W. (2009). "It's a toss up between my hearing, my heart, and my hip": Prioritizing and accommodating multiple morbidities by vulnerable older adults. *Journal of Health Care for the Poor & Underserved*, 20(1), 134-151.

Schram, M. T., Frijters, D., van de Lisdonk, E. H., Ploemacher, J., de Craen, A. J., de Waal, M. W., ... & Schellevis, F. G. (2008). Setting and registry characteristics affect the prevalence and nature of multimorbidity in the elderly. *Journal of clinical epidemiology*, 61(11), 1104-1112.

Schutz, A. (1967). *The phenomenology of the social world*. London: Heinemann Educational Books Ltd.

Schutz, A. (1970). *On phenomenology and social relations*. London: University of Chicago Press.

Scott, J. (1995). *Sociological theory: Contemporary debates*. London: Edward Elgar Publishing.

Shilling, C. (1993). *The body and social theory*. London: Sage.

Shweder, R. A. (2012). Relativism and universalism. In Fassin, D. (Ed.). (2012). *A companion to moral anthropology*. Oxford: John Wiley & Sons Ltd.

Silverstein, M. D., Conroy, S. J., & Gans, D. (2012). Beyond solidarity, reciprocity and altruism: moral capital as a unifying concept in intergenerational support for older people. *Ageing and Society*, 32(7), 1246-1262.

Smith, S. M., Soubhi, H., Fortin, M., Hudon, C., & O'Dowd, T. (2012). Managing patients with multimorbidity: systematic review of interventions in primary care and community settings. *BMJ: British Medical Journal*, 345. doi: e5205.

Spangenberg, L., Forkmann, T., Brähler, E., & Glaesmer, H. (2011). The association of depression and multimorbidity in the elderly: implications for the assessment of depression. *Psychogeriatrics*, 11(4), 227-234.

Starfield, B., Shi, L., & Macinko, J. (2005). Contribution of primary care to health systems and health. *Milbank quarterly*, 83(3), 457-502.

Taylor, C. (1992). *Sources of self*. Cambridge: Cambridge University Press.

Taylor, D., & Bury, M. (2007). Chronic illness, expert patients and care transition. *Sociology of health & illness*, 29(1), 27-45.

The Institute for Public Policy Research. (2009). Towards a smarter state. Retrieved 1st March 2012 from http://www.ippr.org/assets/media/images/media/files/publication/2011/05/smarter_state_1722.pdf

The Institute for Public Policy Research. (2010). Capable communities: public service reform: the next chapter. Retrieved 1st March 2012 from http://www.ippr.org/assets/media/images/media/files/publication/2011/05/capable_communities_1751.pdf

Thoits, P. A. (2011). Mechanisms linking social ties and support to physical and mental health. *Journal of Health and Social Behavior*, 52(2), 145-161.

Townsend, A. (2005). Multiple morbidity and moral identity in mid-life: accounts of chronic illness and the place of the GP consultation in overall management strategies. Ph.D thesis, retrieved 1st November 2011 from <http://theses.gla.ac.uk/2414/>

Townsend, A. (2012). Applying Bourdieu's theory to accounts of living with multimorbidity. *Chronic illness*, 8(2), 89-101.

Townsend, A., Hunt, K., & Wyke, S. (2003). Managing multiple morbidity in mid-life: a qualitative study of attitudes to drug use. *Bmj*, 327(7419), 837.

Townsend, A., Wyke, S., & Hunt, K. (2006). Self-managing and managing self: practical and moral dilemmas in accounts of living with chronic illness. *Chronic Illness*, 2(3), 185-194.

Townsend, A., Wyke, S., & Hunt, K. (2008). Frequent consulting and multiple morbidity: a qualitative comparison of 'high' and 'low' consulters of GPs. *Family practice*, 25(3), 168-175.

Uchino, B. N. (2006). Social support and health: a review of physiological processes potentially underlying links to disease outcomes. *Journal of behavioral medicine*, 29(4), 377-387.

Valderas, J. M., Mercer, S. W., & Fortin, M. (2011). Research on patients with multiple health conditions: different constructs, different views, one voice. *Journal of Comorbidity*, 1(1), 1-3.

Valderas, J. M., Starfield, B., & Roland, M. (2007). Multimorbidity's many challenges: A research priority in the UK. *BMJ: British Medical Journal*, 334(7604), 1128.

Van Der Gaag, M., & Snijders, T. A. (2005). The resource generator: social capital quantification with concrete items. *Social networks*, 27(1), 1-29.

Van der Gaag, M., Snijders, T. A., & Flap, H. D. (2008). Position Generator measures and their relationship to other Social Capital measures. *Social capital: An international research program*, 27-49.

Vassilev, I., Rogers, A., Blickem, C., Brooks, H., Kapadia, D., Kennedy, A., ... & Reeves, D. (2013). Social networks, the 'work' and work force of chronic illness self-management: a survey analysis of personal communities. *PloS one*, 8(4), e59723.

Vassilev, I., Rogers, A., Sanders, C., Kennedy, A., Blickem, C., Protheroe, J., ... & Morris, R. (2011). Social networks, social capital and chronic illness self-management: a realist review. *Chronic Illness*, 7(1), 60-86.

Wadsworth, M. E. J. (1997). Health inequalities in the life course perspective. *Social Science & Medicine*, 44(6), 859-869.

Wasserman, S., & Faust, K. (1994). *Social Network Analysis: Methods and Applications*. London: Cambridge University Press.

Webber, M. P., & Huxley, P. J. (2007). Measuring access to social capital: The validity and reliability of the Resource Generator-UK and its association with common mental disorder. *Social Science & Medicine*, 65(3), 481-492.

Wellman, B. (1998). The place of kinfolk in personal community networks. *Families in the US: Kinship and domestic politics*, 231-239.

Wenger, G. C. (1984). *The supportive network: Coping with old age*. London: Allen & Unwin.

Wenger, G. C. (1991). A network typology: From theory to practice. *Journal of Aging Studies*, 5(2), 147-162.

Wenger, G. C. (1992). *Help in old age: facing up to the challenge; a longitudinal network study*. Liverpool: Liverpool university press.

Wenger, G. C. (1995). A comparison of urban with rural support networks: Liverpool and North Wales. *Ageing and Society*, 15(1), 59-82.

Wenger, G. C. (1997). Social networks and the prediction of elderly people at risk. *Aging & Mental Health*, 1(4), 311-320.

Whittemore, R., Chase, S. K., & Mandle, C. L. (2001). Validity in qualitative research. *Qualitative health research*, 11(4), 522-537.

Wiles, R. (2012). *What are Qualitative Research Ethics?*. London: Bloomsbury Academic.

Wilkie, R., Blagojevic-Bucknall, M., Jordan, K. P., Lacey, R., & McBeth, J. (2013).

Reasons Why Multimorbidity Increases the Risk of Participation Restriction in Older Adults With Lower Extremity Osteoarthritis: A Prospective Cohort Study in Primary Care. *Arthritis care & research*, 65(6), 910-919.

Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health & Illness*, 6(2), 175-200.

Williams, G. (1993). Chronic illness and the pursuit of virtue in everyday life. In Radley, A. (Ed). *Worlds of illness: Biographical and cultural perspectives on health and disease*. London: Routeledge.

Wrong, D. H. (1961). The oversocialized conception of man in modern sociology. *American sociological review*, 183-193.

Appendix 1: Baseline Participant Details

Pseu-donym	Sex M/F	Emple-ment status	Age Group	Social-class / occupation held for most of life	Marital / Accommod-ation status	Self-reported illnesses (in addition to OA and CVD)
Mary	F	Retired	65-74	N/a long-term unemployed	Single, Lives Alone	Mental health (non-specific), asthma, angina, type II diabetes, reactive arthritis (eye), Raynaud's phenomenon, clawed toe.
Ian	M	Retired	65-74	Managerial	Married, Lives with Spouse	Osteomyelitis (as teenager, permanent limitation), glaucoma.
Bill	M	Retired	75+	Routine manual	Married, Lives with Spouse	Asthma, COPD, regular episodic chest infections and stomach ulcers, 'collapsed vocal chords'.
Pamela	F	Retired	65-74	Professional	Married, Lives with Spouse	Rheumatoid arthritis, bunions.
Rose	F	Retired	75+	Skilled non-manual	Single, Lives Alone	Type II diabetes, 'underactive thyroid', glaucoma, 'breathlessness', 'fluid renention', bronchitis.
George	M	Retired	75+	Managerial	Married, Lives with Spouse	Asbestosis, stomach ulcers, prostate cancer (14 years ago, 7 years ago) COPD.
James	M	Retired	65-74	Skilled manual	Single, Lives Alone	Heart attack (10 years ago), prostate cancer (2 years ago).
Theo	M	Retired	65-74	Skilled manual	Married, Lives with Spouse	Heart failure, multiple 'mini strokes', 'clubbed foot' (congenital), mild cognitive impairment.
David	M	Retired	65-74	Skilled non-manual	Single, Lives with Daughter and Grandson	Type II diabetes (borderline), back pain.
Elaine	F	Retired	65-74	N/a Long-term unemployed	Single, Lives Alone	Depression, anxiety.
Isla	F	Retired	75+	Skilled non-manual	Single, Lives Alone	Hip surgery complications (limited mobility and pain), bronchitis.
Mo	F	Employed full-time	55-64	Professional	Single, Lives with Daughter	Systematic lupus, depression, addiction (pain killers)

Judith	F	Retired	65-74	Domestic work	Married, Lives with Spouse	Congenital neuromuscular condition (left side of body significantly impaired, limited mobility), ankylosing spondylitis (neck), vertigo,
Kirsty	F	Employ ed part- time	65-74	Professional	Married, Lives with Spouse	Fibromyalgia, coeliac disease, diverticulitis.
Dan	M	Retired	65-74	Managerial	Married, Lives with Son	Prostate cancer (18 months ago), neck pain / stiffness.

Appendix 2: Social Contact Participants List

Social Contact Name	Name of Patient Participant
Anne	Theo
Geoff	Pamela
Cath	Bill
Sandra	George

Appendix 3: Participant Recruitment by Mailing Batch

Participant Recruitment by Mailing Batch

Mailing batch number	Number of full consents
Batch 1	3
Batch 2	4
Batch 3	3
Batch 4	3
Batch 5	2

Appendix 4: Invitation Letter (Patient Participant)

[Headed Paper]

Dear (Name),

In the past 12 months you have kindly taken part in research in which you completed several questionnaires about your general health; these questionnaires were called the 'General Health Questionnaire' and the 'General Health Monthly Questionnaire'.

In the final questionnaire, you ticked a box suggesting that you would be willing to take part in further research. We are currently asking people if they would be willing to take part in a new study.

The new study is called 'The social networks of people living with multiple chronic illnesses'. This study looks at people's experiences of living with more than one illness, and also the role that friends and family play in their lives.

More details of this new study are enclosed within this letter. We have included a study information leaflet should you wish to find out more about the study. Also enclosed is a consent form, to be signed and returned if you would like to take part in this new study.

If you would like to speak to somebody about the study you can call Tom Porter on: 01782 734721. You can also write to us here at the Arthritis Research UK Primary Care Centre (address below). If you do not want to help with any more research we apologise for writing to you now.

Yours sincerely,

Tom Porter,

PhD researcher.

Appendix 5: Invitation Letter (Social Contact Participant)

[Headed Paper]

Dear Sir/Madam,

Thank you for taking the time to read this letter.

The person that gave you this letter is taking part in an on-going study, this study is called; 'The social networks of people living with multiple chronic illnesses'.

The study looks at people's experiences of health and illness, and also the role that other people play in their lives, such as friends and family.

The person that gave you this letter has suggested that you are important in their life. We would like to hear your views about this person's health, the role they play in your life, and also the role you play in their life.

If you would like to help us with this study, we would like to invite you to take part in a short interview – either in person or by telephone. We have included a study information leaflet should you wish to find out more about the study. Also enclosed is a consent form, to be signed and returned if you would like to take part in this study.

If you would like to speak to somebody about the study you can call Tom Porter on: 01782 734889. You can also write to us here at the Arthritis Research UK Primary Care Centre (address below). If you do not want to help with this research we apologise for writing to you now.

Yours faithfully,

Tom Porter,
PhD researcher.

Appendix 6: Study Information Leaflet (Patient Participant)

[Headed Paper]

Study title: The social networks of people living with multiple chronic illnesses

You are invited to participate in the above study which is being conducted within the Arthritis Research UK Primary Care Centre at Keele University.

This leaflet explains what will happen if you agree to take part in this study. Please take time to read the following information carefully and discuss it with others if you wish. If you would like to discuss anything with a member of the team, please call Tom Porter Tel: **01782 734721**.

What is the purpose of the study?

The purpose of this study is to understand people's experiences of living with more than one chronic illness at any one time.

The study also looks at how people's experiences of illness are shaped by the people around them, such as family, friends, and work colleagues.

We hope that by understanding these issues, we may be able to contribute to the development of services that better meet the needs of people living with multiple illnesses.

Do I have to take part?

No, you are free to decide whether or not to take part.

You have been chosen because, when you filled in a questionnaire earlier this year, you agreed to further contact. The questionnaire was called "The general health questionnaire".

If you do decide to take part you will be asked to sign a consent form (enclosed). If you decide to take part you are still free to withdraw at any time, and without giving a reason.

Your decision as to whether or not to take part in the study, or any decision to withdraw from the study, will not affect the treatment you will receive, or any legal rights.

If you would like to take part, please complete and return the enclosed consent form and we will contact you.

Please turn over

What will happen to me if I take part?

If you choose to take part, we would send you two questionnaires (spaced between three and six months apart), and invite you to take part in two interviews about your health (again, spaced between three and six months apart).

At the beginning of the study you would complete one questionnaire and one interview, then, at a time of your choice between three and six months later, you would complete the second questionnaire and the second interview.

The questionnaires

The questionnaires are designed to help us understand which people you are in contact with on a day-to-day basis. Each questionnaire asks you to record the people that you are in contact with over a 7 day period; this takes the form of a 7 day diary. In this diary you may name any person that you wish.

Upon completion of this 7 day diary, the questionnaires ask some questions about the people you have recorded; questions include their age, their sex, and how close they live.

The interviews

The interviews will focus upon your experience of living with more than one illness at the same time, and also the role that other people play in your life.

Each interview will last approximately 1 hour, and can be arranged at a time and place that is best for you. During the interview, you can choose not to answer questions, or to end the interview at any time, and for any reason.

We would like to audio-record the interviews, the interviews will then be typed out; this is called a transcript. The transcript will be fully anonymised and will not bear any information that would identify you by name. Both the tape and the transcript of the interviews will be kept in a secure location and will only be used by researchers directly concerned with this study.

We will ask you if you would like a copy of the transcripts of your interviews. We will store the tapes securely for 20 years, and after this time they will be destroyed.

Quotations from the interview may be used in reports of this study. Your identity will be hidden in any such report, and you will not be identified personally. The fact that you have taken part in the study will not be revealed to anyone outside the research team. If the interview contains comments or information that might identify a third party, or an institution (e.g., a GP, clinic or hospital), we will ensure

that the person or institution cannot be identified in any account or published report of this study.

During the interviews, you can choose not to answer questions, or to end the interview at any time. Any information that you give in the interview will not be passed on to anyone else without your permission.

In addition to the two questionnaires and the two interviews, you will be given the option to contribute in two further ways. These include;

Monthly update letter

Each month, you would receive a letter via post, asking you about your recent health and the role of other people. If you felt that something important had occurred or changed in that month, and you felt you wanted to share these experiences, we would provide an opportunity for you to do so. You may wish to take part in a short telephone interview; this would be done at your convenience. We would continue to send you a monthly update letter until your second questionnaire. Each monthly letter also allows you to indicate that you do not wish to take part in the study.

Interview with an 'important' other person

Because we are interested in the role that other people play in your experience of health and illness, we would welcome the opportunity to interview someone you identify as being important in your life, such as a family member or a friend.

This interview would focus on this other person's understanding of your illness, and the role they play in your life.

If you were agreeable to this part of the study, you would choose the person to be invited to take part in the interview. You would then pass on information about the study, and that person could contact us if they wanted to take part. This person would then be invited to take part in a short interview.

This interview would last approximately 30-60 minutes and would be audio-recorded and transcribed in the same way as your interviews. We would not discuss your interview or any of your personal information with this person. We will ask you about this part of the study at the end of your interviews.

How long will it take?

If you complete the two questionnaires and two interviews, it will take approximately 6 hours.

If you would like to take part in additional interviews following the monthly update letter, this may add another 2 - 4 hours.

What are the possible risks and benefits of taking part?

There are no direct risks relating to medical treatment in this study nor is there intended to be any direct medical benefit. There may be an indirect benefit to you and other patients from the insights we gain from this study, but we cannot be sure about this.

Sometimes during interviews like these, a small number of people may feel some distress, for example, an interview topic might bring back unhappy memories or distressing thoughts. If this happens and you do not wish to discuss the issue further, the topic will not be followed up again during the interview. Furthermore, you may end the interview at any point. In the event that any interview were to become upsetting, we would like to make sure you are supported; we would be happy to stay in touch or visit you if you wished, or, should you prefer, we will direct you towards your GP.

Who is organising and funding the research?

This study is part of a programme of work into osteoarthritis being conducted by the Arthritis Research UK Primary Care Centre at Keele University. The study is being funded by Arthritis Research UK.

Who has reviewed the study?

The North West Cheshire Research Ethics Committee has approved this study.

What should I do if I have a complaint?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (contact Tom Porter tel: **01782 734721**). If you remain unhappy, and wish to complain formally you can do this. Details and advice about making a complaint may be obtained from your local Patient Advice and Liaison Service (PALS) (telephone 01606 544444).

How can further information about the study be obtained?

We will be glad to answer any questions that you may have about this study. You can call us at the Arthritis Research UK Primary Care Centre, Keele University on (01782) 734721. Please ask for Tom Porter who is one of the researchers working on this study. You can also email us at t.porter@ipchs.keele.ac.uk or write to us at the address below.

Thank you for taking the time to read this leaflet

Appendix 7: Study Information Leaflet (Social Contact Participant)

[Headed Paper]

Study title: The social networks of people living with multiple chronic illnesses

You are invited to participate in the above study which is being conducted within the Arthritis Research UK Primary Care Centre at Keele University.

This leaflet explains what will happen if you agree to take part in this study. Please take time to read the following information carefully and discuss it with others if you wish. If you would like to discuss anything with a member of the team, please call Tom Porter Tel: 01782 734721.

What is the purpose of the study?

The purpose of this study is to understand people's experiences of living with more than one chronic illness at any one time.

We hope to speak to people living with chronic illness, and also the people in their lives that they identify as being important in some way.

The study looks at how people's experiences of illness are shaped by the people around them, such as family, friends, and work colleagues.

By better understanding these issues, we hope that we may be able to contribute to the development of services that better meet the needs of people living with multiple illnesses.

Why have I been invited?

You have been invited to take part in this study because Mrs Kathleen Walley has identified you as being important in their life.

We are interested in understanding your views on your relationship with Mrs Walley and the role you play in their life.

Do I have to take part?

No, you are free to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form (enclosed). If you decide to take part you are still free to withdraw at any time, and without giving a reason.

Your decision as to whether or not to take part in the study, or any decision to withdraw from the study, will not affect any treatment you may receive, or any legal rights.

If you would like to take part, please return the enclosed consent form and we will contact you.

What will happen to me if I take part?

If you decide to take part, you will be invited to take part in a short interview about your relationship with Mrs Walley and the role you play in their life.

The interview can be conducted in person or by telephone, and at a time and place that is best for you. During the interview, you can choose not to answer questions, or to end the interview at any time, and for any reason.

We would like to audio-record the interview, the interview will then be typed out; this is called a transcript. **The transcript will be fully anonymised and will not bear any information that would identify you by name.** Both the tape and the transcript of the interview will be kept in a secure location and will only be used by researchers directly concerned with this study.

We will ask you if you would like a copy of the transcripts of your interview. We will store the tapes securely for 20 years, and after this time they will be destroyed.

Quotations from the interview may be used in reports of this study. **Your identity will be hidden in any such report, and you will not be identified personally.** If the interview contains comments or information that might identify a third party, or an institution (e.g., a GP, clinic or hospital), we will ensure that the person or institution cannot be identified in any account or published report of this study.

How long will it take?

The interview may be conducted in person or via telephone, and will be arranged entirely at your convenience. The interview will last between 30 and 60 minutes.

What are the possible risks and benefits of taking part?

There are no direct risks relating to medical treatment in this study nor is there intended to be any direct medical benefit. There may be an indirect benefit to you and other people from the insights we gain from this study, but we cannot be sure about this.

Sometimes during interviews like these, a small number of people may feel some distress, for example, an interview topic might bring back unhappy memories or distressing thoughts. If this happens and you do not wish to discuss the issue further, the topic will not be followed up again during the interview. Furthermore, you may end the interview at any point.

Please turn over

In the event that the interview were to become upsetting, we would like to make sure you are supported; we would be happy to stay in touch or visit you if you wished, or, should you prefer, we will direct you towards more formal support such as your GP.

What should I do if I have a complaint?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (please call Tom Porter in 01782 734721). If you remain unhappy, and wish to complain formally you can do this. Details and advice about making a complaint may be obtained from your local Patient Advice and Liaison Service (PALS) (telephone 01606 544444).

Who is organising and funding the research?

This study is part of a programme of work into osteoarthritis being conducted by the Arthritis Research UK Primary Care Centre at Keele University. The Study is being funded by Arthritis Research UK.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for compensation against Keele University but you may have to pay your own legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Who has reviewed the study?

The North West Cheshire Research Ethics Committee has approved this study.

How can further information about the study be obtained?

We will be glad to answer any questions that you may have about this study. You can call us at the Arthritis Research UK Primary Care Centre at Keele University on (01782) 734721. Please ask for Tom Porter who is one of the researchers working on this study. You can also email us at t.porter@ipchs.keele.ac.uk or write to us at the address below.

Thank you for taking the time to read this leaflet

Appendix 8: Consent Form (Patient Participant)

[Headed Paper]

Patient participant consent form

Study title: The social networks of people living with multiple chronic illnesses

This form signifies that you consent to take part in this study. You are reminded to **read the information letter** about this study before giving consent to take part. Please tick where appropriate:

1. I confirm that I have read and understand the information leaflet (**version 2.1 dated 12.12.2012**) and have had the opportunity to ask questions and have had these answered satisfactorily.....
2. I understand that my participation in the study is voluntary. I also understand that I may withdraw at any time, without giving any reason, and that this does not affect my medical care or legal rights.....
3. I understand that I will be sent two postal questionnaires (over a **three to** six month period).....
4. I understand that I will be contacted about participating in two interviews about my health (over a **three to** six month period).....
5. I understand that I will be contacted monthly (**in the months between first and second interview/questionnaire**) and given the opportunity to participate in further interviews about my health and wellbeing.....
6. I understand that the interviews will be taped and transcribed, but will bear no personal identifying information. I also understand that the tapes will be stored in a secure location for 20 years and after this time they will be destroyed.....
7. I understand that relevant data collected during the study, may be looked at by individuals from the Arthritis Research UK Primary Care Research Centre at Keele University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.....
8. I understand that quotations from the interview may be included in reports or publications from this study, but that these will be anonymous and I will not be identifiable.....

9. I give permission for my medical records to be reviewed **in confidence**.....

I agree to take part in the study.....

Name.....

Signed

Date.....

Thank you for your help with this study. If you have any further questions about the study please contact Tom Porter on 01782 734721.

To be completed by the researcher:

Name of researcher.....

Signed..... Date.....

Appendix 9: Consent Form (Social Contact Participant)

[Headed Paper]

Social contact consent form

Study title: The social networks of people living with multiple chronic illnesses

This form signifies that you consent to take part in this study. You are reminded to **read the information leaflet** about this study before giving consent to take part. Please tick where appropriate:

Yes

1. I confirm that I have read and understand the information leaflet (version 1.2 dated 21.12.2011) and have had the opportunity to ask questions and have had these answered satisfactorily.....
2. I understand that my participation in the study is voluntary. I also understand that I may withdraw at any time, without giving any reason, and that this does not affect my medical care or legal rights.....
3. I understand that the interview will be taped and transcribed, and the transcript will bear no personal identifying information. I also understand that the tapes will be stored in a secure location for 20 years and after this time they will be destroyed.....
4. I understand that relevant data collected during the study, may be looked at by individuals from the Arthritis Research UK Primary Care Research Centre at Keele University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.....
5. I understand that quotations from the interview may be included in reports or publications from this study, but that these will be anonymous and I will not be identifiable.....
6. I agree to take part in the study.....

Name

Telephone number

Signed.....

Date.....

Thank you for your help with this study. If you have any further questions about the study please contact Tom Porter on 01782 734721.

To be completed by the researcher:

Name of researcher.....

Signed.....

Date.....

Appendix 10: Confirmation of Interview Letter

[Headed Paper]

Study title: The social networks of people living with multiple chronic illnesses

Dear (Name),

Thank you for agreeing to participate in the above study. This letter is to confirm the time and date for your interview with a member of the research team.

Your interview is scheduled for [Time and date]

If you have any further queries, or would like to arrange for a more convenient time and/or date, please contact Tom Porter on Tel: 01782 734 721.

Yours sincerely,

Tom Porter,
PhD researcher.

Appendix 11: Interview Topic Guide (Patient Participant)

Explain the study – I hope to understand how people live with more than one illness as the same time. I am also interested in the role that other people play in your life and the role you play in other people's lives.

Explain the interview: All is confidential, I will not discuss anything from this interview with your family /friends/other social contacts or anyone outside the research team.

You do not have to answer any of the questions, and you can stop the interview at any time. Confirm audio-record.

Multiple chronic illnesses

- Tell me about your general health?
- Do you consider any of your conditions to be more important than other conditions?
 - Why do you think this is?
- Do you feel that the doctors or health-services understand what is important to you?
 - Why do you think this is?
- How do you manage your different conditions?
- How do you manage your day-to-day activities?

Social network

You recently completed a questionnaire in which you recorded the people you were in contact with over a week:

- Was this week usual or unusual in any way?
- Is there anyone that is important in helping you with your health?
- How does your health affect how/when/why you see people?
- Do you do things for other people?
- Do you think that your health has changed your relationship with anyone?

Appendix 12: Interview Topic Guide (Social Contact Participant)

Explain the study – I hope to understand how people live with more than one illness as the same time. I am also interested in the role that other people play in the lives of people with multiple illnesses.

Explain the interview: All is confidential, I will not discuss anything from this interview with your family /friends/other social contacts or anyone outside the research team.

You do not have to answer any of the questions, and you can stop the interview at any time. Confirm audio-record.

- Tell me about this person's general health?
- Do you consider any of this person's conditions to be more important than any other conditions?
 - Why do you think this is?
- Do you feel that doctors or health-services understand what is important to this person?
 - Why do you think this is?
- What role do you play in this person's life?
- What role do they play in your life?
- Do you think that this person's health has affected your relationship?

Appendix 13: Social Network Diary Cover Letter

Dear (name),

Study title – The social networks of people living with multiple chronic illnesses

Thank you for agreeing to take part in the above study.

Enclosed is a questionnaire which we would ask you to complete and return in the enclosed pre-paid envelope.

This questionnaire has two sections. Section 1 is called 'Your daily diary'. In section 1, you are asked to record the people that you are in contact with over 7 days. You should record the names of people that you meet face to face, and also the people you are in contact with by telephone, by letter, or by email etc. This may include a partner, family members, friends, work colleagues, or even strangers.

Section 2 is called 'Details of your contacts'. In section 2, you are asked some questions about each of the people you recorded in section 1, you should complete a row of questions for each of these people.

This study aims to better understand the role of other people in shaping the experience of illness. In completing sections 1 & 2, you will be helping us to understand the type of people that you are in contact with over a week. We will discuss these issues further in your interview. If you have any issues at all, or would like to speak with someone about how to complete the questionnaire, please feel free to contact Tom Porter Tel: 01782 734 721.

Once you have completed sections 1 & 2, please return the questionnaire in the enclosed pre-paid envelope.

Yours sincerely,

Tom Porter,

PhD Student

Appendix 14: Social Network Diary

Section 1 – Your daily diary

Over the next 7 days, please use the diary below to record the people that you are in contact with.

Please feel free to record any person that you have been in contact with. It would be helpful to record all the people that you are in contact with, including those people you meet face-to-face, but also those that you are in contact with by telephone, by letter, or by email etc.

Please record any contact that feels 'important' to you. The people you record will often be people that you already know, such as family and friends. However, sometimes you may not know the person very well or they may even be a stranger to you.

You do not need to record people's full names; a first name and initial is all that is needed (e.g. Joe B). Where you do not know a person's name, record them as 'unknown 1', 'unknown 2', 'unknown 3' etc.

The following is an example of how each day should be completed:

Day 1 example - Who were you in contact with today?

James J, Sarah J. and Unknown 1.

In this example you met with James J, and Sarah J. There was also contact with a third person – 'Unknown 1' – although you did not know their name, you chatted for some time and they felt quite important to you.

Day 2 example - Who were you in contact with today?

Sarah J. and Unknown 2.

In this example, you wrote a letter to Sarah J. You also chatted with a local person – you do not know their name, however, this chat was quite important to you, so they are recorded in your diary as 'Unknown 2'.

If you have any questions, please contact Tom Porter:

01782 734 721

Your daily diary begins overleaf

Your Daily Diary

Day 1: Who were you in contact with today?

Day 2: Who were you in contact with today?

Day 3: Who were you in contact with today?

Day 4: Who were you in contact with today?

Day 5: Who were you in contact with today?

Day 6: Who were you in contact with today?

Day 7: Who were you in contact with today?

Finally, if there are any 'important' people in your life that you have not contacted in the 7 days, record their names here:

Section 2 – Details of your contacts

Now that have completed section 1, please complete the table below. For each person recorded in section 1, complete a row of information. In cases where you did not know a person's name, record their name as 'unknown 1', 'unknown 2' etc, and complete as much of the row as possible. The survey provides enough space for up to 25 people, if you require additional pages or have any questions, please contact Tom Porter on: 01782 734721.

Person 1	Their age?	Their sex?	Their relationship with you?	How important is this person to you?	How long have you known this person?	How many miles away does this person live?
Name _____	_____ Years	Male/Female _____	1 – Family 2 – Friend 3 – Neighbour 4 – Other (please state) _____	1 – Very important 2 – Fairly important 3 – Not particularly important 4 – Not at all important _____	_____ Years _____ Months	_____ Mile(s)

Person 2	Their age?	Their sex?	Their relationship with you?	How important is this person to you?	How long have you known this person?	How many miles away does this person live?
Name _____	_____ Years	Male/Female _____	1 – Family 2 – Friend 3 – Neighbour 4 – Other (please state) _____	1 – Very important 2 – Fairly important 3 – Not particularly important 4 – Not at all important _____	_____ Years _____ Months	_____ Mile(s)

Appendix 15: Monthly Update Sheet (Patient Participant)

Study: The social networks of people living with multiple chronic illnesses

Monthly update sheet

- **This month, have there been any developments in your health and wellbeing?**

- ☐ No, nothing this month
- ☐ Yes, but I do not wish to be contacted
- ☐ Yes, and I would like to be contacted about my experiences this month

- **In your interview we discussed the role of other people in your life. This month, have there been any developments in the role that other people play in your life?**

- ☐ No, nothing this month
- ☐ Yes, but I do not wish to be contacted
- ☐ Yes, and I would like to be contacted about my experiences this month

- ☐ **I do not wish to take part in this study anymore**

If you would like to speak to the researcher, please ring Tom Porter on tel: 01782 734 721.

Please return this form in the envelope provided

Appendix 16: NRES Letter (Request for Further Information)



Health Research Authority

NRES Committee North West - Cheshire

Research Ethics Office
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7821
Facsimile: 0161 625 7299

16 December 2011

Mr Thomas Porter
Arthritis Research UK Primary Care Centre
Primary Care Sciences
Keele University
ST5 5BG

Dear Mr Porter

Study Title: The social networks of people living with multiple chronic illnesses
REC reference number: 11/NW/0825

The Research Ethics Committee reviewed the above application at the meeting held on 08 December 2011. Thank you for attending to discuss the study along with your supervisor Professor Ong

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Covering Letter		12 November 2011
Evidence of insurance or indemnity	Lockton - Keele University	21 July 2011
Interview Schedules/Topic Guides	Thematic Interview Guides - Patient Participant - Version 1	31 October 2011
Interview Schedules/Topic Guides	Social Contact - Version 1	31 October 2011
Investigator CV	Tom Porter	31 October 2011
Investigator CV	B N Ong	03 October 2011
Investigator CV	Tom Sanders	
Letter from Sponsor	Keele University	11 November 2011
Letter of invitation to participant	Patient Participant Invitation - Version 1	31 October 2011
Letter of invitation to participant	Social Contact Invitation - Version 1	31 October 2011
Other: Social Network Questionnaire Cover Letter	1	31 October 2011
Other: Confirmation of Interview Letter	1	31 October 2011
Other: Monthly Update Sheet	1	31 October 2011
Participant Consent Form: Patient Participant Consent Form	1	31 October 2011

Participant Consent Form: Social Contact Consent Form	1	31 October 2011
Participant Information Sheet: Study Information Leaflet (Patient Participant)	1	31 October 2011
Participant Information Sheet: Study Information Leaflet (Social Contact)	1	31 October 2011
Protocol	1.0	07 November 2011
Questionnaire: Social Network Questionnaire	1	31 October 2011
REC application	3.2	17 November 2013

Provisional opinion

1. The Committee queried why the tapes will be stored securely for 20 years and then destroyed after this time. They asked whether they could be destroyed once the tapes were transcribed. You explained that this is the standard procedure. Professor Ong commented that the tapes will be digitally recorded; however, she clarified that the guidance given by your professional association is that tapes must be stored securely for 20 years and that standard procedures are to be adhered to.
2. The Committee asked what provisions were in place if a participant was to become distressed during the interview. You clarified that if somebody was to become upset you will offer your support as a researcher as much as possible. Professor Ong commented that the interview would be stopped and the participant would be offered help and support and they will be advised to contact their GP. The Committee advised that this information needs to be detailed in the Information Sheets. You agreed.
3. The Committee commented that the interview guide was not very explicit in terms of what types of questions will be asked; it looks more like a page with words on. The Committee would like to see an actual interview schedule stating the questions that will be asked of the participants. You agreed. You commented that your aim was to try to leave enough leeway for individual participants to direct the conversation. The Committee explained that it would help the participant to understand what the researchers wish to know. You agreed.
4. The Committee noted that the Information Sheets need to be checked for grammatical errors and require tidying up. There is no explanation of what will actually happen to participants and the details are not in a concise enough way. Information is needed on what the participant's personal involvement will be. There is also no information on the optional extra and what that will be. You agreed to revise the Information Sheets accordingly.
5. The Committee asked how distress would be dealt with if a participant decided to take part in the short telephone interview and became upset during it. You agreed that it would be more complicated to gauge distress over the telephone. Professor Ong clarified that they have a lot of experience of this and a lot of studies have included this method. The hope is that you would have built up a rapport with the participants over time and if somebody was to become distressed they would discuss it with you who could deal with it within the conversation. The option would be given to participants for you or somebody else to come and visit them over the next few days following the phone call if they wished. The Committee advised that this information should be included in the Information Sheet. You agreed.

- b. Under the heading 'Do I have to take part?' the first word should be 'No.'
 - c. Details need to be included on what the process would be if participants were to become distressed during the face to face and telephone interviews.
 - d. Under the heading 'What will happen to me if I take part?' The bold statement needs to be revised to clearly state that the transcripts will be anonymised.
 - e. The monthly telephone calls could potentially take up more time than is suggested and a more realistic time should be stated as this could be quite burdensome for some participants
 - f. Include the following standard complaints paragraph 'If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [contact number]. If you remain unhappy and wish to complain formally, you can do this [insert details eg NHS Complaints Procedure or Private Institutional arrangements]. Details can be obtained from [insert details]'
 - g. Include the following standard indemnity paragraph 'In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against [name of Sponsor Organisation, NHS Trust, Private Clinic] but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).'
3. The Committee would like to see the Patient Participant Information Sheet revised as follows:
 - a. Indicate a more realistic timeframe of how long it will take to fill out the diary and how long they will be involved in the research.
 - b. Indicate that social network contacts can be named on the Diary.
 4. The Committee would like to see the Consent Forms revised as follows:
 - a. Revise point one to include reference to the version number and date of the information leaflet. Also include the following wording at the end after 'questions' and have had these answered satisfactorily.'
 - b. The word 'understand' needs to be written as one word rather than 'unders tand'. This affects most of the points on the consent forms.
 - c. Include the following mandatory statement 'I understand that relevant data collected during the study, may be looked at by individuals from [company name], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.' On the patient participant consent form, this paragraph would replace point 9.
 5. The Committee would like to see the Diary revised to indicate to the participants that they can choose to enter details of any social network contacts they have been in contact with over the past 7 days.
 6. The Committee would like to see the Monthly Update Sheet revised to include an extra box under each question to allow the participant to answer as follows 'Yes, but I do not wish to talk about it.'

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact our co-ordinator, Miss Shehnaz Ishaq via email Shehnaz.ishaq@northwest.nhs.uk or telephone 0161 625 7821.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 14 April 2012.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/NW/0825

Please quote this number on all correspondence

Yours sincerely



Mr Jonathan Deans
Chair

Email: Shehnaz.ishaq@northwest.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to: Ms Jackie Gray
Arthritis Research UK Primary Care Centre
Primary Care Sciences
Keele University
Keele
Staffordshire
ST5 5BG

Ms Yvonne Lochhead
Central and Eastern Cheshire Primary Care Trust
Universal House
ERF Way
Middlewich
CW10 0JQ

Professor Bie Nio Ong
Arthritis Research UK Primary Care Centre
Primary Care Sciences
Keele University
Keele
Staffordshire
ST5 5BG

Dr Tom Sanders
Arthritis Research UK Primary Care Centre
Primary Care Sciences
Keele University
Keele
Staffordshire
ST5 5BG

Appendix 17: NRES Letter 2 (Confirmation of Ethical Approval)



Health Research Authority

NRES Committee North West - Cheshire

Research Ethics Office
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7815
Facsimile: 0161 625 7299

30 January 2012

Mr Thomas Porter
Arthritis Research UK Primary Care Centre
Primary Care Sciences
Keele University
ST5 5BG

Dear Mr Porter

Study title: The social networks of people living with multiple chronic illnesses
REC reference: 11/NW/0825

Thank you for your letter of 03 January 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		12 November 2011
Covering Letter		11 January 2012
Evidence of insurance or indemnity	Lockton - Keel University	21 July 2011
Interview Schedules/Topic Guides	Thematic Interview Guides - Patient Participant - Version 1	31 October 2011
Interview Schedules/Topic Guides	Social Contact - Version 1	31 October 2011
Interview Schedules/Topic Guides	Patient Participant Interview Schedule - Version 1.2	21 December 2011
Interview Schedules/Topic Guides	Social Contact Interview Schedule - Version 1.2	21 December 2011
Investigator CV	Tom Porter	31 October 2011
Investigator CV	B N Ong	03 October 2011
Investigator CV	Tom Sanders	
Letter from Sponsor	Keele University	11 November 2011
Letter of invitation to participant	Patient Participant Invitation - Version 1	31 October 2011
Letter of invitation to participant	Social Contact Invitation - Version 1	31 October 2011
Other: Social Network Questionnaire Cover Letter	1	31 October 2011
Other: Confirmation of Interview Letter	1	31 October 2011
Other: Monthly Update Sheet	1.2	21 December 2011
Other: Daily Diary - Altered Page	1.2	21 November 2011
Participant Consent Form: Social Contact Consent Form	1.2	21 December 2011
Participant Consent Form: Patient Participant Consent Form	1.3	11 January 2012
Participant Information Sheet: Study Information Leaflet (Social Contact)	1.2	21 December 2011
Participant Information Sheet: Study Information Leaflet (Patient Participant)	1.3	11 January 2012
Protocol	1.0	07 November 2011

Questionnaire: Social Network Questionnaire	1	31 October 2011
REC application	3.2	17 November 2013
Response to Request for Further Information		10 January 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/NW/0825	Please quote this number on all correspondence
------------	--

With the Committee's best wishes for the success of this project

Yours sincerely


Mr Jonathan Deans
 Chair

Email: shehnaz.ishaq@northwest.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting*

"After ethical review – guidance for researchers"

Copy to:

Ms Jackie Gray
Arthritis Research UK Primary Care Centre
Primary Care Sciences
Keele University
Keele
Staffordshire
ST5 5BG

Ms Yvonne Lochhead
Central and Eastern Cheshire Primary Care Trust
Universal House
ERF Way
Middlewich
CW10 0JQ

Professor Bie Nio Ong
Arthritis Research UK Primary Care Centre
Primary Care Sciences
Keele University
Keele
Staffordshire
ST5 5BG

Dr Tom Sanders
Arthritis Research UK Primary Care Centre
Primary Care Sciences
Keele University
Keele
Staffordshire
ST5 5BG

Appendix 18: NRES Letter 3 (Confirmation of Ethical Amendment)



Mr Tom Porter
Arthritis Research UK Primary Care Centre
Primary Care Sciences
Keele University
ST5 5BG

Date 15 January 2013

Dear Mr Porter

The social networks of people living with multiple chronic illnesses

CSP Ref: 71767

Amendment Identifier: (2)04_Jan_13

Date REC approval: 15 January 2013

I am pleased to confirm that Cheshire & Merseyside Comprehensive Local Research Network (CLRN) have reviewed the above amendment in accordance with the Research Governance Framework, using the co-ordinated system for NHS Permission (CSP) and can confirm that all research governance reviews have been satisfied to enable this amendment to take place at the following sites:

- Central and Eastern Cheshire PCT

Subject to the following conditions:

- There will be no call upon PCT resources other than those identified and agreed.

If you have any further questions regarding this or other research you may wish to undertake please feel free to contact me. We wish you every success with your research.

Yours sincerely

A handwritten signature in black ink, appearing to read "Karen Tripp", is located below the "Yours sincerely" text.

Karen Tripp
Research Management & Governance Officer
Cheshire & Merseyside CLRN
karen.tripp@rlbuht.nhs.uk
0151 331 5138

Appendix 19: Example of Anonymised Interview Transcript

- I: Okay. There we go. So, basically, all I really know about yourself is that you completed those questionnaires [yeah]. And I think the people that completed those questionnaires had some kind of osteoarthritis [yeah], and some kind of cardiovascular condition [yeah], so like blood pressure or, that and the other. So, I'm assuming that you've got a couple of conditions there?
- IV: No, I've got diabetes, thyroid...what else have I got? Blood pressure and, er, fluid retention. I don't think I want much more, do I?
- I: No [laughs], that's enough, I'd have thought, is it? And...and do you have arthritis as well?
- IV: Yes, I've had both me knees done, operated on, you know, renewed, but they're going old now.
- I: Is it just in the knees that you have...?
- IV: No, I've got it in me back, and all me elbows and, and been, since I've been on this [01:03 – metformin] for me diabetes, I get nothing but blooming cramp [right], in my hands now, and it's most annoying.
- I: Is that something you put directly down to that, the medication?
- IV: Well, apparently it does, that does cause it, for diabetes [yeah], so they tell me, so I don't know.
- I: No, no, okay, but that would, that would...
- IV: But I don't want any more tablets, I'm sick of them.
- I: Really?
- IV: I've just ordered some; I ordered them now. God, there's about 14 things I have to order. So, er...

I: Is that quite a major part of...

IV: Well, I take 9, 13, 14 tablets a day, and you get sick and fed up of them. And they say you should take them at different times; if I had to take them at different times I'd never get them down. What I do, I put them all in my hand and I just...with a drink, else they'd never go down [yeah]. So, whether they fight or whether they work properly, I don't know, but I certainly couldn't take them one at a time like some people do.

[Door slams]

Oh, God, I hope he remembers to put my black bin out.

I: Do you want me to chase after him?

IV: Yeah, if...

I: Or I can do it when I leave, if you want?

IV: Will you, do you mind? [No] It's just at the corner.

I: Yeah, no problem.

IV: Only I can't take it out and the man downstairs does, but he's on holiday, so it...

I: Okay. Yeah, no problem.

IV: Will you. Oh, bless you.

I: So, you said you had 14 different pills a day? [Yeah] So, you're supposed to take them, kind of, at breakfast and then throughout the day?

IV: No, I take them at breakfast...oh,, I take some at breakfast and some at night. The [02:38 – metformin] I take in a morning and teatime, and I also take a statin at night [uh-huh]. And, that's all I take at night, them three. But the others are just fluid tablets, blood pressure tablets. Don't ask me what they're for [yeah].

But I don't take many painkillers now, I've stopped them, because I found the painkillers weren't helping me, like, but they were making me feel lousy, you know, I felt as if I wanted, oh, I'd dose off all the while. So, I've been suffering. I've had a bad leg this last week, but I haven't gone back on painkillers, and it is going easier now, so I'm hoping it goes before I go to XX (Europe). I daren't go to the doctors in case he tells me I can't go [laughs].

I: Yeah. So the painkillers, do you get painkillers on prescription or [yeah], yeah, and you don't take those?

IV: Co-codamol and they say take two in a morning and two at night. They make me feel lousy, and [00:02 -that's it].

I: Uh-huh. So, you've stopped taking your painkillers. Do you take, all the others as your, as the doctor would tell you to, or...?

IV: Oh, yes, I take all the others. I religiously do as I'm told [00:23] tablets [yeah]. Because I'm always told, 'Don't stop taking this one or that one. You must [00:29], no, don't stop taking that one,' you know, when I go in and ask if I can drop them off. 'No.' So, now, I just don't ask, I just keep taking them [hmm]. And if he adds another on, then I want to know why [laughs].

I: Yeah, how do you feel when they do that though, when they say...?

IV: Oh, I just feel, oh, God, I'm, I'm just sick of taking tablets [hmm]. And, of course, with the hypertension, the water tablets, rather, I can't go out in a morning for two hours, because I'm spending me time in the blooming bathroom [hmm], and you just get fed up with it. Same as when I fly to XX (Europe), I usually go about 6 o'clock in the morning. Well, I have to take the fluid tablets at 12 o'clock at night, and then I'm in and out of bed. Oh, it's, once I get there I'm all right [uh-huh], but that's the bit of a bug bind with it.

I: So, you've got to, kind of, plan ahead, I guess, to...?

IV: I have to plan ahead with it, yeah.

I: Yeah. Is it just the, kind of, water tablets that that's with or is it...?

IV: Yeah, it's, er, water...

I: Is there any, any side effects from the other, any of the other pills that you're on that you think [01:35 – participants talking over each other]?

IV: No, I don't think so, because I've had this, I've had it... I had an operation, oh, God, when I was 40, and, er, I've been taking them since then, fluid tablets, and they've had to strengthen them and give me different ones because of me blood pressure. So, don't ask me what they're all for, because I don't know [hmm], and I don't want to know.

I: You don't want to know?

IV: No, I say, 'I'll take them but I don't want to know.' [Laughs]

I: Yeah, okay. So, erm, in terms of just trying to understand the overall picture of your health, you said, erm, you've got diabetes. What type is that?

IV: Two.

I: And, erm, thyroid?

IV: Er, I take 50mls of, er, [02:26 – thyroxine] a day [uh-huh] for that. It's, er, underactive [yeah], so...

I: The blood pressure?

IV: That is up and down. It's usually - just lately, when I've gone to the doctors, it's keeping itself fairly low, you know [okay], it's not been too high.

I: Erm, the arthritis, well, you've had your knees done, but you said it's also in your back and your elbows and...?

IV: Yeah, oh, it's all over me. This, this leg's worse. Well, I've fell down that many times on my knees, and, er, I think I've probably knocked something out of place in this one. But, I won't go...they keep grumbling at me and saying I should go to the hospital, but once

you've had them done, you're not going to have them done again, if you can help it [hmm], so I keep managing on walking sticks [uh-huh]. And after all, I'm 83, why put yourself through pain when you've no need to, you can manage? [Hmm]. I could...well, I could still drive, I'm deciding I'm not going to drive anymore, for the simple reason I've lost my confidence [yeah], you know, when you [3:40 - see] all these cars [hmm] buzzing past, and I've had one or two near misses with people passing and, and I don't go slow myself, I'm not a slow driver, so I've decided I shall only cause trouble for somebody one day, so I'll pack it in while I can.

I: I see, okay.

Is there anything else, in terms of your health, that you can think of that, kind of...?

IV: Oh, I've got glaucoma, that's another thing I've got, in this eye [yeah], and that doesn't help matters ...

I: No, no [laughs].

IV: So, er...

I: I'm assuming that you're on, er, medication for that as well?

IV: Yeah. Yeah, I, well, I have to go to XX hospital with that. And I have to have, erm...well, I had my eye x-rayed for diabetes in June, and I've got to have it done, when the six months is up, it's getting near now, I've got to have it x-rayed again this time [uh-huh], as the, it's beginning, my diabetes is beginning to affect the eye. So, I don't know what they'll do [uh-huh], but, er...oh, well, I don't know, I keep forgetting, I, I put it in the back of my mind.

I: Yeah, yeah.

IV: It's no good worrying about them. They're there, they'll come, and they'll go.

I: Yeah.

IV: So, I mean I've had six children and I'm very, very lucky, they're all healthy and they're all really good to me. And, er, I've got, er, 12 grandchildren. I've got 12 great grandchildren. So, I'm not lonely [laughs].

I: No [laughs], exactly the opposite I'd have thought, yeah.

IV: Oh, God, aye.

I: So, in terms of, health, then, is that everything that you'd think, you think you could, you can think of that's...?

IV: Yeah. I can't get out and about. I can't walk far I'm breath...I get breathless. But, they checked my heart out and they said it's not that. Something here, but it's gone no farther, so I'm not bothering them, I'm still going.

I: Yeah, yeah, yeah.

IV: They'll send for me if they decide to do anything.

I: Yeah, okay.

IV: But, it does annoy me when I'm out, and I want to go somewhere and then me back'll start aching. I used to have injections in my spine, well, back [yeah], but they stopped doing them. I think it's because I've got to the age I am, they don't do them, only for so long [okay], so I don't get them anymore, which were, they weren't nice, but they did ease it after a while.

I: Uh-huh, hmm... just so – you've got a - so there are a number of different, kind of, things, conditions, that you're living with [hmm]. I'm just trying to understand, are any of them, on a day-to-day basis, are any of them more important to you than the others?

IV: I think the fact that I can't get about and can't, I can't bend down very well and pick things up, and me use is going in me hands, I think them are the things that really get me [uh-huh], because my mind's pretty alert; I do forget things. But, it's me hands and me legs that are, and me back, that are the thing and same as me breathing.

I: Because?

IV: I can't get out and...I mean, going up and down stairs, I do make myself, though, go up and down stairs to keep me legs going, but mainly, now, I use me lift. I shouldn't use it all the while but I'm getting idle.

I: [laughs] [07:26].

IV: And then I've got that chair but that damn thing's not working at the moment, the flaming thing.

I: It's gone, has it gone, has it?

IV: Well, the motor's gone. My son took the chair to pieces and took it in his factory and checked it all out, and there's nothing wrong with that. He thought it'd jammed in, oh, this thing underneath it, but it hadn't. So he's put it all back together, and then he was going to XX, golfing, Saturday morning I got a message, 'Mother, don't get in touch with XX. I know what's up with that chair,' he said, 'it's a switch.' I says, 'All right,' but I'd already rung them and they wanted £60 to come out. And I argued with them and said I was a pensioner and this, that and the other. It was only eight months old. Anyway, I couldn't get...I said, 'Oh, well, you'll have to come then, I'll have to have it.' And just after I'd done all that he rings up to tell me, 'Don't get XX Mother, I know what it is.' I thought, 'Blimey.' So, er, he was supposed to come and do that at dinnertime today, finish it, but he's all golf [laughs].

I: [laughs] Yeah. But he's dropping in lunchtime to sort that?

IV: Yeah, well he's got a factory at XX.

I: Oh, okay.

IV: XX Engineering.

I: One, and, er, he's one of six kids, is he?

IV: Yeah, he's one of them, yeah. He's the third lad. The eldest lad's in XX. He's been there, good God, 40 years.

I: Really? Yeah, yeah.

IV: And then XX (Son), he lives up, erm, oh, [09:06 – XX. And then I've got another one that's in XX (local), the oldest lad, XX (Son). He does car repairs. He's got a place at XX (son's) factory, where he does car body repairs [yeah]. And, er, XX (Daughter) works at XX (Local), the one girl, and the other girl lives down XX (South), which is XX (Grandson's) mother.

I: Aah, right.

IV: She's down XX (South). She's, er, in charge of a big kitchen, a school kitchen [yeah]. So, I don't...we ring each day, but I don't see so much of her.

I: Yeah, okay.

IV: But the others are in and out all the while.

I: Literally visiting [yeah] all the time?

IV: Yeah. And then, same as he was on about XX (Granddaughter), he told me XX (Granddaughter) might be calling round later on, well, she's XX's daughter. But XX (Daughter) comes up most days [uh-huh], to see if I'm all right. And if they don't come, 'Are you all right Mother?' I don't know what they told if I told them I wasn't.

I: [laughs] Yeah.

IV: Oh, me tea's gone cold. I don't know what he's give me that big cup for.

I: It's a bucket, yeah.

IV: Yeah, it's me breakfast cup.

I: Oh, I'm the same. I have a big bucket.

IV: I can't do with a, halfway through me breakfast, having to go and get another cup of tea...

I: No, it's not worth the while, is it, yeah? Erm, so the, so the six kids, well, obviously, apart from the couple that are living a way away, they're in and out? [Yeah] What about the, your grandkids, are they...?

IV: Yeah, they're in and out?

I: How old are they? Well, like, the oldest and the youngest?

IV: The eldest great grandchild is 17, and the youngest is just starting school, four.

I: Oh, wow, okay.

IV: But the others are all grown up.

I: And the grandchildren?

IV: I've got one grandchild who is 14, but the others are all in their 20s.

I: Right, okay, yeah. Are they, kind of, in and out all the time? Are they local and...

IV: Well, they're in touch with me all the while.

I: Yeah, great.

IV: Yeah, I don't get a lot of peace [laughs].

I: No, no, it's...

IV: It sounds ungrateful but there's time when I think, 'Oh, I'll have half an hour now,' and somebody comes. Still, I should be grateful really.

I: Is that, is it – I know, like, we, I often feel like that with my family, is it, but is that genuinely something you feel, like, that you do get too much attention?

IV: Oh, you can get too much. Well, XX, his wife kicked him out; she didn't love him anymore. And he's got three children. One's 14, the other's 10, the other's 6. Well, he

came and stopped with me because he'd nowhere else to go, and the kids used to come three nights a week.

Well, this place was like a tip, and I've just got it sorted out. But their little bedroom you couldn't get in for junk, and there was a bed in there which they used to sleep in, but it was just chaotic [hmm]. And, er, that did, it got me down a bit, they were here 12 months, and that was a bit too much. Because, plus, the others were grumbling at me and, my family, and saying, 'Well, Mother, you must tell him he's got to make the children do.' I did, but he didn't [hmm], because he was worried about losing his children [uh-huh] and [tut], well, life isn't easy, you know.

I: No, no. But it can be a bit of a double-edged sword then.

IV: Well, it was getting, really getting me down, because, I mean, this place, they were...oh, the furniture and everything was a mess and carpet. It really did drive me daft.

[Noise]

Oh, it's the lawn cutter.

I: I thought that was a big wasp.

I'm just gonna stop this and turn it off a bit if, er, he's going to start that. So just bear with with...

[Interruption]

There we go. You should be able to hear it over the lawnmower [yeah].

What were we saying? Oh, yeah, we were just chatting, chatting about your family.

So, I'm assuming that if you need anything...

IV: They're there.

I: ...any help or that?

IV: Yeah, same as, I wanted some shopping and I just write, I wrote a list and asked XX if he'd come and do it. Well, he doesn't go on work till half past one, so [uh-huh], of course, he come and did it, did it.

And, XX, who he lives with, she comes on a Saturday afternoon and cleans all through and does all through for me. And then XX (daughter) will come during the week and she'll run the Hoover round. But I can't do a lot of things now, which annoys me [hmm]. But, er, oh, I'm looking forward to going to XX (Europe) [laughs].

I: so people who come and do your shopping and Hoover through for you, that, kind of, thing. Erm...

[Loud lawnmower noise]

IV: Oh, go home.

I: Is that something that you, kind of, need to ask for, or is that something that people do for you automatically?

IV: Well, they ask me if I'm all right, if I want anything [yeah], or...I don't actually have to ask them for it.

I: Is it – do you ever feel as if you couldn't say, 'I need something doing,' for one reason or another, or...?

IV: Well, I do feel that they do a lot for me, and I don't like asking [yeah], but in the end I'd probably have to ask. Or if I'm talking to one of the others and I say, 'Oh, God, I shall have to get our Ian or our John to do so-and-so,' it gets back to them.

I: Yeah, aah.

IV: You know, they have discussions, discussions about Mother, I think.

I: [laughs] So they, so, they'll, er, so it'll work its way through to [yeah] someone else who...?

IV: It gets round, yeah.

I: Okay, and that, that...

IV: Or if I'm talking to XX from XX (South), she'll be ringing up to XX (Son) or one of the others, and she'll tell them. So it's quite, a little chain that goes round [laughs].

I: Yeah. I suppose in a sense that must be quite nice though?

IV: It is nice. I live here on me own now. I lived here before XX come. My husband died 10 year, 11 years ago, and I've been on me own since then.

And I love my little flat, me tree out here [uh-huh], and, XX (Son) bought it for me, so the flat is mine. And, er, he did all this up, re-carpeted, carpeted it all through, and painted it while I was in XX (Europe). Well, I knew when I come back I'd got a new back kitchen and everything. So I was quite pleased when I got back, it was a bit of a shock [laughs].

I: Fantastic.

IV: I knew that he was going to do something in, to me...no, I asked him to clean the carpet in here and clean the suite, but when I come back there was a new carpet and new suite [uh-huh], so I got rather a shock.

I: Yeah, fantastic. Just what you want when you come back from holiday as well.

IV: Yeah, oh, it really...

I: Picks you up.

IV: ...did me for the winter, I'll tell you.

I: Yeah, I bet.

IV: Yeah. I knew they were doing something but...and when we come back we had [04:32] 'Oh, I've got to go and get some bread, they've got no bread.' And I thought, 'They've got no bread, what's going on?' And they were trying to finish putting the lights up in the back kitchen before we got here [laughs]. Oh, God.

I: It's like on, er, something off the television show, isn't it [yeah], the surprise.

IV: Well, he wasn't going to do the back kitchen [yeah], and then on the Friday, as I was coming back on...no, on the Sat...Fri...yeah, that was it, the Friday, as I was coming back on the Sunday; he decided to do the back kitchen. And they'd got that back kitchen in and ripped the other out and everything by the time I, we got back.

I: Fantastic. It's a lovely job as well, isn't it?

IV: Yeah, well [fantastic] XX, his son, is a plumber, and the other son is a general bugger about, I might as well say what I think [laughs].

I: [laughs] Yeah.

IV: And, between them they got all that done, and got everybody in helping and sorting out, so I just couldn't believe it when I walked in the back kitchen.

I: Fantastic.

IV: Because my husband had done it about 30 years ago and it was dated [hmm]. We had brown cupboards and, of course, it had gone all white.

I: Uh-huh, yeah, lovely.

IV: So, yeah.

I: Is there anything, like, you, that you feel you can't ask for?

IV: I don't really think there is. I know I'm going to have a struggle telling them I don't want to drive anymore [uh-huh]. They're going to try to...'You'll lose your independence Mother.' But, there again, I haven't had me car for weeks, XX's got it, he's using my car. So it means that I haven't got a car here if I want one [hmm]. And then he takes me everywhere, because he's got the car, so I've not been driving, you see. And at my age I don't think you want to. I had to stop quick the other day and then I got cramp in me blooming leg after I'd stopped. And it's an automatic car [uh-huh], and I thought, 'Oh, God XX, you're not having this.' But, I suppose it...

I: So, you think, you think that, you said you're going to struggle, be a struggle to tell them that, so they're...

IV: They're going to try and persuade me not to give up driving [hmm]. Because I've been expecting them to tell me I can't drive because of my eyes, but the trouble is, I can sit here and I can read that number on that car down there and the one behind it [uh-huh]. I've no dist... I've no trouble with it. And the optician says, 'You've no need to worry about losing your licence with your eyes.' So, er, but it's not me eyes, it's me. I see old people and I see them making mistakes, and I think, 'Oh, God, do I do that?'

I: Yeah, yeah.

IV: You know, you see them going, er, slow, about 20 mile an hour sometimes, and you're stuck behind them, and I think, 'Oh, God, I'm not like that am I?' Or if you're in the car with someone and they say, 'Oh, God, why don't they get a move on?' And I look and it's old people, and I think, 'No, XX, you give it up. You'll get to that stage yourself if you're not careful.' [Laughs]

I: uh-huh.

IV: So, before I get to that stage I'm packing it in.

I: Okay. So that might be a bit difficult telling, persuading them that that's the right thing to do?

IV: Yeah, because XX (son) bought me the car, you see. I only tax and insure it.

I: Okay.

IV: That's what I say I'm looked after hand and foot.

I: Yeah. But with that comes - that's what you said, you, are you worried about telling because they've bought you the car, are you...?

IV: No, er, I'm worried that they'll try and make me go on driving [hmm], not give it up, but I'm rather determined to this time [okay]. Besides, I go out in it once a week, well, I'm paying,

it's a big engine, it's, er, 220, or whatever it is, for the tax, and the insurance was 500 odd [hmm]. Well, I think that's a lot for going out just once a week in it. I can get a taxi, call for a taxi, and get a taxi to run me to the XX and to the shops, if need be [uh-huh]. So, er...

I: Okay. But that – I mean, I, I initially asked, if there's things you can't ask for, or, but there's not - there's always – there's some - are there some people that you can ask things of that you can't ask of other people, kind of, thing, or...?

IV: I don't really know, they're all pretty good, you know. But I'm a bit independent [hmm]; I don't like asking. And I think, 'No, I'm not asking you [yeah],' and then somebody will come along and say, 'Oh, Nan, do you want so-and-so?' 'Oh, yes, all right.' [Laughs]

I: Okay, yeah.

IV: It's - that's how it goes, you know.

Appendix 20: Publications and Presentations Arising from this Study

Presentations

2013. '*Social Resources and Health: a gift exchange perspective*', British Sociological Association, Medical Sociology Annual Conference.

2013. '*A sociology of the gift for contemporary policy*', British Sociological Association Annual Conference.

2013. (Invited speaker) '*The role of patients' social networks in shaping the experience of musculoskeletal conditions*', British Society for Rheumatology Annual Conference.